



Children's hospice
and family support

NEWS

Edition 1 | 2018



WELCOME TO A
**VERY SPECIAL
EDITION**

Inside you will discover the
impact of your incredible support



“FROM THE CEO

Welcome to the first edition of our brand new newsletter.

Last month we sent a survey to all supporters asking you to share your thoughts, opinions and insights to help us better shape our communications and services. Thank you to everyone who responded.

By learning what motivates you to support Very Special Kids and the areas of our work you are most passionate about, we are better equipped to communicate with you, and together we can make an enormous impact for those in need.

This new edition of our newsletter is in direct response to your feedback. We have listened and are bringing you all the latest information on our support services and stories focusing on the impact of your support. Because if it wasn't for your generosity and compassion, we simply couldn't do the important work we do.

This year we have introduced two new support services for families: a new transport assistance service for regional families in partnership with the Royal Flying Doctor Service (more on page 4), as well as securing funding to provide physiotherapy for children during their stay at the Very Special Kids hospice.

Despite these achievements, we are still faced with the challenging goal to raise \$8 million this year to continue providing a high standard of services. Through the support of generous corporate partners and community donors we know we can achieve amazing things and create greater impact together.

Michael Wasley,
Chief Executive Officer

Continuity of care

OUR FAMILY SUPPORT TEAM IS AN INTEGRAL PART OF VERY SPECIAL KIDS AND WITHOUT THEM, THERE WOULD BE A LARGE GAP IN THE SERVICES WE OFFER.

Read a unique insight into the role from one of our practitioners.

"Very Special Kids provides holistic family care to more than 900 families across Victoria with ongoing support from diagnosis through to bereavement. I have been a part of the team as a social worker for almost six years now. I think of myself as a co-creator, building authentic relationships with families in an effort to provide choice at all stages of care. We provide a unique level of intervention that values longevity of support. Integral to this process is understanding the family as a system and favouring a flexible model of care rather than adopting a one-size-fits-all approach.

We live in a culture that has been largely unwilling to accept the sad fact that children do die and that we have an obligation as a community to adopt a village mindedness when it comes to caring for these children and their families. We must all bear witness and, without a doubt, providing families with choice at end of life lays at the heart of this commitment.

I have been with families as they navigate the terrain of death and the oceanic tidal waves of their grief. We stay involved indefinitely after the death of a child and this continuum of care offers me privileged insight into the lessons grief teaches us about what it means to be human."

- Jessica Birnbaum,
Family Support Practitioner
and Deputy Manager



HELPING HAND

COVER STORY



Braybon family: Veneta, Barkley (dog), Macey, Henry, and Darren

Honouring Macey

MACEY BRAYBON CAME TO VERY SPECIAL KIDS IN JANUARY 2016 FOR END-OF-LIFE CARE, WHEN SHE WAS JUST 11-YEARS-OLD.

Below is a tiny snapshot of what it has been like for Macey's Mum, Veneta. We thank her for bravely agreeing to share what's in her heart.

“ My beautiful daughter, Macey was diagnosed with a brain tumor in December 2014, and passed away on 15 January 2016.”

Here are five things about parental grief that if I could, I would tell the world...

1 Hearing my daughter's name in conversations is like music to my ears, a sparkling ray of light on a drab day. Macey's horrendous journey of medical treatments, pain and suffering took its toll, so much so, it seems surreal. I often find myself questioning if I ever really had a daughter, if Macey was ever really here, and to hear her name tells me she was.

2 The overwhelming pain of losing Macey is heart wrenching and debilitating. There are times when I am so consumed with this pain that I cannot do anything but sit and cry.

3 People no longer treat me as they used to. Neighbours will cross the street in order to avoid me, friends will not return my calls and there are friends that we no longer hear from. I understand. I know this is because they find it difficult to speak to me. They don't know what to say. They don't want to upset me. But what they don't realise is that avoiding me only adds to my pain.

4 Some days are better than others, and it is difficult to predict how a day is going to turn out. However, there are special occasions we know will be extra tough. I am always grateful for a sign from loved ones. A telephone

call, or a text can lighten the heavy cloud of grief. It reminds us that we are supported.

5 People often say to me, "You are amazing, how do you manage to keep going every day?" The truth is I am not amazing. I am a mother to another child Henry, who needs me, even more so now that he has lost his only sibling. I get up every day and put on a brave face. I take him to school, kiss him goodbye, and I go off to work. What people don't see is that I am pretending. I am pretending that everything is ok. I do this for Henry, for myself, but most of all I do this as a way of honouring Macey.

Grieving the loss of our Macey is a journey we continue to struggle with. The amazing and ongoing support provided to us and our extended family, by Very Special Kids, is something that we are eternally grateful for."



JESS PROVIDES COUNSELLING AND BEREAVEMENT SUPPORT FOR THE BRAYBON FAMILY.

Road to respite

VERY SPECIAL KIDS HAVE LAUNCHED A SIGNIFICANT PARTNERSHIP WITH THE ROYAL FLYING DOCTOR SERVICE (RFDS) TO ENABLE REGIONAL FAMILIES LIVING WITH A TERMINALLY ILL CHILD THE OPPORTUNITY TO ACCESS RESPITE CARE.

Thanks to over \$156,000 of funding from the William Buckland Foundation, Road to Respite is a joint initiative of the two charities, providing free-of-charge transport for regional children with life-threatening conditions to Very Special Kids Hospice in Malvern.

Eadweard's sister Morag and mother Sarah help him cut the cake to mark the start of the new service.

Over a two year pilot program, the Road to Respite van, donated by Ambulance Victoria, will transport up to 90 children to Victoria's only children's hospice where they will receive specialised 24-hour nursing care free-of-charge giving their parents a much needed break.

One of the families that have benefited from the new service is the Chignell family from Bendigo.

Ten-year-old Eadweard Chignell was born with early infantile SCN1A encephalopathy, an extremely rare genetic disorder, so rare he's one of only nine in



the world with the condition. Eadweard can't walk or talk, has regular seizures and requires 24-hour-care for all his basic needs.

Parents of five, Sarah and Stuart say the Very Special Kids Hospice is their only respite and because of where they live and the complexity of Eadweard's condition, they can stop up to five times in one trip, adding a great amount of time and stress to every drive.

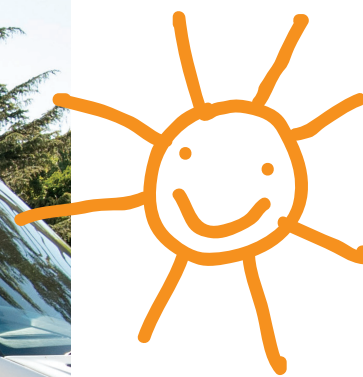
"Having Eadweard picked up and dropped off.. meant I could give our other children my undivided attention."

"We always have to allow extra travel time for things like feeds, controlling seizures and vomiting, nappy changes and to reposition him if he's uncomfortable" says mother and full-time carer Sarah.





Representatives from Very Special Kids, Royal Flying Doctor Service, William Buckland Foundation, Ambulance Victoria and the Chignell family



RESPONDING TO THE NEEDS OF REGIONAL FAMILIES

In 2016, 165 regional families supported by Very Special Kids participated in a survey to gauge the need for a transport service which highlighted the circumstances or barriers that limit their access to the Very Special Kids Hospice. Key findings showed 68% of regional families surveyed have never accessed Very Special Kids Hospice before due to travel and distance. An additional 72% of families agreed they would increase their use of the Very Special Kids Hospice if transport assistance was available.

"There's been times where I've had to stop on the side of the road to monitor his seizures. Another time he bit his tongue whilst having a seizure in the car and we had to spend a night in hospital."

The family first trialled the Road to Respite service in October last year and found it made a huge difference.

"Having Eadweard picked up and dropped off by the van was fantastic. It took a lot of stress out of driving a long distance and freed up a significant amount of time for respite and meant I could give our other children my undivided attention."

The Chignell family booked the Road to Respite service again last month and took a much deserved camping trip.

"Because of Eadweard's condition he can't participate in many family activities. Instead

he went on his own holiday to Very Special Kids which he loves and we went camping. Without the new service we wouldn't have booked our camping trip as it would have been too hard"

Michael Wasley, CEO of Very Special Kids, says "this unique partnership will help overcome the barriers that restrict regional families from accessing much-needed support services.

Using RFDS expertise in healthcare and transportation, we are delighted to be providing safe transport at no cost, reducing fatigue in carers and increasing the health and well-being for children and their families."

SPECIAL DATES

WALK FOR PHIL

Friday 20 April, 7am to 3pm

23km walk from Moonee Valley via Flemington Racecourse to Caulfield Racecourse followed by a celebration event

AUTUMN CLASSIC

Friday 18 May, 7am to 2.30pm

Grounds of Very Special Kids, Malvern

A virtual cycling race where teams compete on an indoor trainer

MAYDAY

Friday 18 May, 12pm to 3pm

Regent Plaza Ballroom, Melbourne

The annual Mayday charity event is a sports-themed charity lunch organised by The Corcous Club

24 HOUR TREADMILL CHALLENGE

Friday 25 May to Saturday 26 May 2018, 9am to 9am

Grounds of Very Special Kids, Malvern

Brings over 1,000 participants together to keep treadmills in continuous motion for 24 hours

ART WITH HEART

Thursday 14 June, 6.30pm to 9pm

Eleven 40 Studio, Malvern

Art exhibition and live auction of fine paintings and sculptures from leading contemporary artists

FASHION SALE

Saturday 16 June 2018, 9am to 3pm

Malvern Town Hall, Malvern

Up to 90% off thousands of new ladies and men's quality clothing items, jewellery and accessories

TO GET INVOLVED AND HELP SUPPORT VERY SPECIAL KIDS VISIT VSK.ORG.AU/EVENTS



Q&A
with...

24 HOUR TREADMILL CHALLENGE LEGEND ANDREW WELLS

In 2013 Andrew, General Manager at Epic Pharmacy, became involved in the 24 Hour Treadmill Challenge, one of Very Special Kids' largest annual fundraising events. Over the last six years he has stunned other participants with his efforts and unique wardrobe choices.

Q What motivated you to become involved?

A We had a link to Very Special Kids through our friendship with the Evans family and their son Jack. Having seen the fabulous support given to the family over a number of years we decided that the 24 Hour Treadmill Challenge was a great avenue to support the children's charity. The activity aspect of the challenge fits in with our profile as a health care company and the concept really appealed to us.

Q What is your favourite thing about the 24 Hour Treadmill Challenge?

A Every year the atmosphere and camaraderie of the challenge blows me away. Whether it is 9am or 3am, people are there to give their all. Over the years I have met many people and seeing familiar faces year after year is a great aspect of the challenge and one I look forward to. The generosity of people both within the Very Special Kids family and my wider circle of friends is something for which I am extremely thankful.

Q What keeps you coming back every year?

A I think knowing that we are able to help make a difference is something that keeps me coming back. The difference Very Special Kids makes to a family's life is amazing.

One on one care for children with high supervision needs

THANKS TO A VERY GENEROUS DONATION FROM THE GAUDRY FAMILY, VERY SPECIAL KIDS HAVE SECURED FUNDING TO PROVIDE A 1:1 RATIO OF NURSING AND PERSONAL CARE STAFF TO SUPPORT CHILDREN WITH BEHAVIOURAL CHALLENGES DURING RESPITE.



Over the last three years, there has been a steady increase in children accessing the hospice who have high supervision needs due to challenging behaviour.

Children with challenging behaviours can be unaware of their own safety and the safety of others which could lead to self-harming as a way of communicating and expressing frustration, or unintentionally harming others.

These children are generally mobile and like to explore their surroundings and without a high level of supervision while doing this, it could lead to putting themselves or the safety of others at risk.

Very Special Kids Hospice Manager Sue Kearney says "we have an obligation to keep everyone safe, it's always at the forefront of

what we do. We always have two nurses and two carers on every shift except when a high supervision child comes to stay. Then we arrange an additional staff member to provide one-on-one care."

Last year, 42 bed nights were accessed by children on behavioural support plans.

The cost associated with providing one-on-one care by a personal care worker for 42 nights is \$49,728 per year. For a registered nurse, the cost is much higher at \$98,826.

"Now that we have secured funding to cover these costs, it takes an enormous amount of pressure off" says Sue.

"It gives families peace of mind, knowing that their child is being supervised and cared for in the best way possible. It also has a knock on effect for staff as they know they are working in a safe environment and can be reassured they have the best support to be able to carry out their job safely and effectively."



THE IMPACT OF YOUR DONATION

Providing one-on-one care for children with behavioural challenges in the hospice would not be possible without the generous support of long-term financial and corporate donors, Anton and Jenny Gaudry.

The Gaudry family were first touched by the work of Very Special Kids when they were involved as a service provider and over the years have attended several fundraising events and provided ongoing support.

"To hear how an ordinary family one day is transformed into needing continual medical and family support is heart breaking. But we were heartened by the fact an organisation like Very Special Kids can achieve such fantastic outcomes with support from the community. A child with special needs impacts so many lives, all of whom can do with support" says Anton Gaudry.

Late last year, the Gaudry family donated \$50,000 to fund the one-on-one support program in the hospice and have created a lasting impact.

"We were pleasantly surprised our donation could go such a long way and I strongly encourage others to join us in supporting Very Special Kids."

**THROUGH THE KINDNESS
AND GENEROSITY OF FAMILIES
LIKE THE GAUDRYS, VERY SPECIAL
KIDS CAN CONTINUE SUPPORTING
FAMILIES FREE-OF-CHARGE.**



**Yes, I want to
support Very
Special Kids
today!**



My donation

I would like to make a gift of:

☐ \$50 ☐ \$100 ☐ \$500 ☐ \$1,250

Or my choice: \$ _____

My info

Name: _____

Address: _____

Postcode: _____

Phone: _____

Mobile: _____

Email: _____

Date of birth: _____

My payment

☐ I would like to donate by
cheque / money order
(payable to Very Special Kids)

OR please debit my credit card:

☐ VISA ☐ Mastercard ☐ AMEX

Card number:

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Expiry: ____ / ____

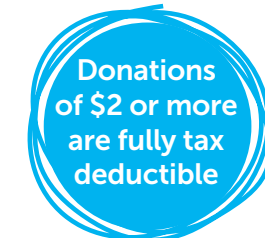
Signature: _____

Name on card: _____

Send to

Very Special Kids

321 Glenferrie Road,
Malvern, Victoria, 3144
Phone: 03 9804 6222
Fax: 03 9822 1252
Email: mail@vsk.org.au



THANK YOU

“Jaz was 3-years-old when Very Special Kids started supporting us, and in a few months I was thinking, how did we ever survive up until this point?”

– MICK, JAZMIN'S DAD



IN THE LAST YEAR BECAUSE OF YOU...

933

Families are supported

2,401

bed nights of hospice care

545

hospice admissions

1,035

nights in family accomodation

6,002

family support sessions

THANK YOU