



# The hidden health crisis

Children's cancer needs more than medicine

## About Redkite

When a family is told their child has cancer, what they hear is “your child might die”. When your child’s life is in question, it can feel impossible for families to hold it together and keep functioning, not only for their sick child but for one another.

Redkite is a lifeline for these families, providing the critical emotional and mental health support, financial assistance, and information and resources they need throughout the long and traumatic cancer experience.

When a family’s life is shattered by childhood cancer, Redkite is there to help and has been for almost 40 years. As an independent, not-for-profit service provider which receives no government funding, the programs and services Redkite provides are funded by our corporate partnerships, contributions from trusts and foundations, and donations from the general public. We have grown to a \$13 million charity, providing essential services to families facing childhood cancer in every paediatric hospital and in every community across Australia.

The services we provide address the essential non-medical needs of children with cancer and their families and are critical to ensure families survive the trauma and impacts of childhood cancer.

### **Acknowledgement**

We wish to thank the following individuals who assisted in developing the content for this report.

- The parents and young people who had experienced childhood cancer and who formed Redkite’s Lived Experience Advisory Group, for sharing their experiences with us. Your input across this project has been so valuable in helping us better understand and advocate for the needs of all families living with paediatric cancer.
- All 713 parents and carers who took the time to respond to the national survey to share what living with paediatric cancer is like for their family. We appreciate your time and input, and thank you for generously sharing your stories and challenges.
- Dr Bill Callaghan, Director at Strategic Mapping, for his data analysis support and advice.

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# Executive Summary

There is a misconception that in Australia, if you have a child with cancer, the healthcare system has all the resources available to support you and your family unconditionally throughout your child's entire cancer journey. While it's true that we have some of the highest standards of healthcare and survival rates from paediatric cancer in the world, it's not true to say families receive the holistic support they need to manage the short and long-term impacts of their child's cancer. There have been strides made by non-profits and the health sector in recent years, however, it is still very much an under-resourced area and families are not receiving all the support they need.

Redkite's programs and services address families' broader, more complex psychosocial needs which extend – largely unseen and unacknowledged – beyond the hospital walls. In 2020, as demand for Redkite's services reached unprecedented levels, we sought to identify and quantify the extent to which families' support needs along the entire length of their cancer experience were not being met. From diagnosis to treatment and after treatment, paediatric cancer is a complex trauma where few family members are left unscathed, and this trauma can have a ripple effect across the entire community. We needed to understand the scale of the problem, identify who was missing out, when, and what kind of support they needed.

Redkite's family needs survey set out to reveal and quantify the gaps in support for families facing childhood cancer throughout their cancer experience. In total, 713 parents and carers of a child (aged 0-18 years) diagnosed with cancer between 2010 and 2020 responded to the survey.

## Five significant areas for concern were identified:

1. The greatest gaps in support are after treatment ends and in bereavement
2. There are clear gaps in emotional and mental health support across the whole family
3. In particular, support is lacking for the emotional and mental health of the child living with cancer
4. The gaps are even more significant for their siblings
5. There is a need for greater connection with other families

## Families were at even more disadvantage if:

- Anyone in their family had to relocate for treatment
- They lived in a regional or remote location
- They were the mother of the diagnosed child
- The diagnosed child had experienced a relapse
- They were Aboriginal and Torres Strait Islander

While it was clear there were high levels of need across all stages of the cancer experience, family needs were least likely to be met at end of treatment onwards and during bereavement – and the scale of the issue is considerable. We estimate that in Australia, there are around 2,600 paediatric cancer families not getting the specialised emotional and mental health support they need from end of treatment onwards. This is alongside around 1,100 bereaved families who are not getting enough support to live with their grief and loss<sup>1</sup>.

**We estimate 10,000 mums, dads, diagnosed children and their siblings are missing out on the specialised emotional and mental health support they need to cope with childhood cancer.**

<sup>1</sup> Figure extrapolation based on Australian paediatric cancer prevalence and 5-year survival estimates from the Australian Institute of Health and Welfare, as well as estimated length of time that families will need support in the community.

While the predominant focus is medical treatment when it comes to childhood cancer, it is also critical to address and support the long-term wellbeing of the entire family. Redkite's mission is to be a lifeline for these families, providing essential non-medical support to help them as they navigate the uncertainty and trauma of cancer, and manage its long-term impacts on all family members. We are committed to ensuring more children and families get the support they need – whether they are in hospital or at home, no matter where they are located in Australia, at every stage of their cancer experience.

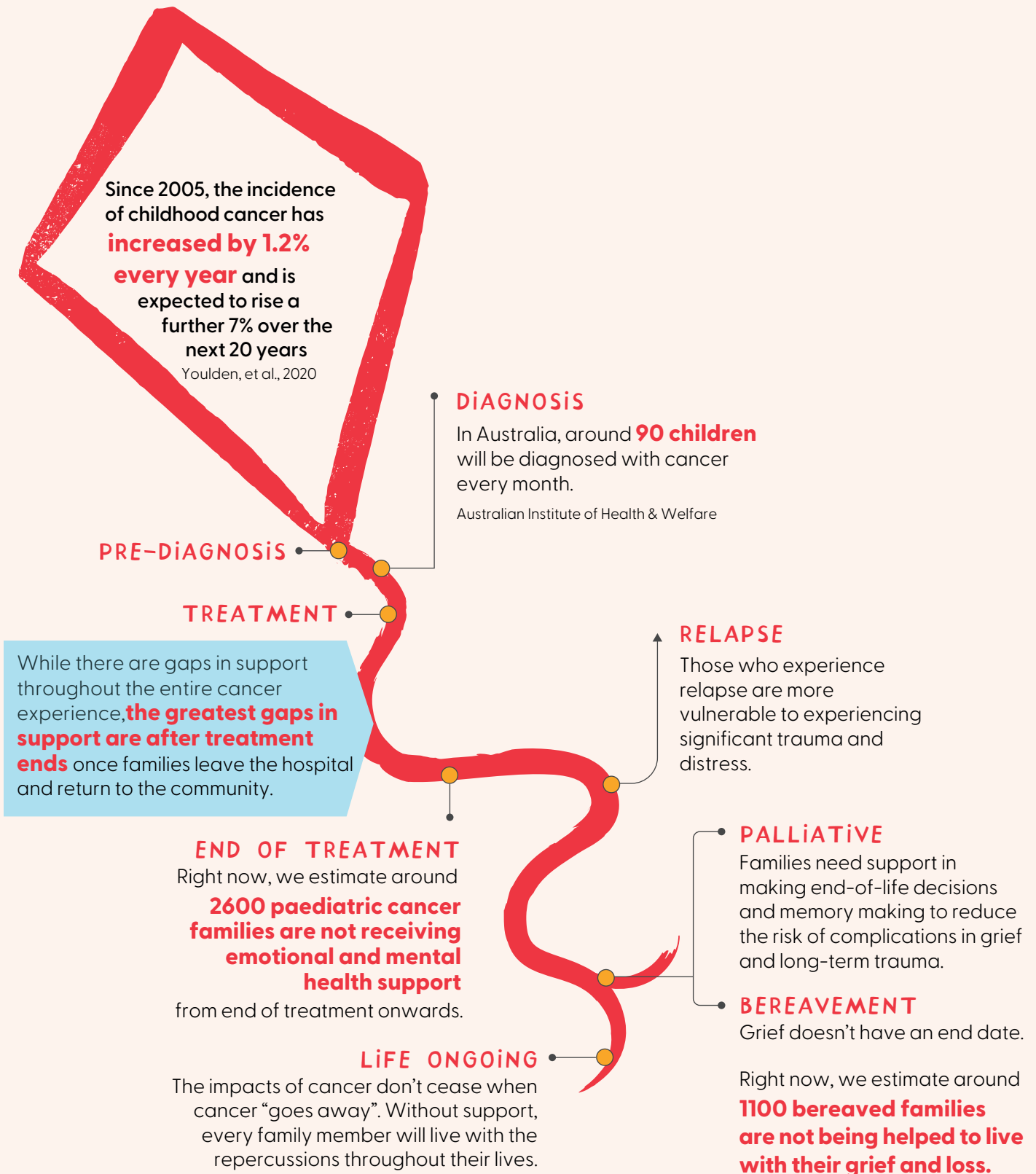
Based on our research findings, we need to continue investing in services that better support families in their transition from hospital to the community; increase the capacity of our practitioners to deliver specialised support specifically tailored to the emotional and mental health needs of children, including the diagnosed child and their siblings; and become stronger advocates alongside bereaved families to ensure their voices and needs are heard.



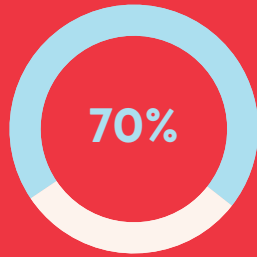
# Snapshot

## THE SCALE OF CHILDREN'S CANCER IN AUSTRALIA AND ITS HIDDEN HEALTH CRISIS

Right now, we estimate **10,000 mums, dads, carers, diagnosed children and their siblings** are missing out on the emotional, and mental health support they need to cope with childhood cancer across the entire cancer experience.



# KEY SURVEY FINDINGS



of families said they did not get the support they needed for their longer-term emotional and mental health from the end of treatment onwards

According to parents, children with cancer are struggling with their emotional & mental health...



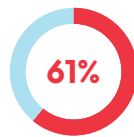
had emotional and mental health support gaps at **diagnosis and during treatment**



had emotional and mental health gaps at **end of treatment onwards**



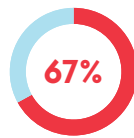
...And the gaps in support are even more significant for their siblings



siblings had emotional and mental health support gaps at **diagnosis and during treatment**



siblings had emotional and mental health support gaps from the **end of treatment onwards**



siblings had emotional and mental health support gaps during **palliative care**

Families from regional or remote areas experience greater difficulties than those in metro areas...

**71%**

vs

**82%**

of families in metro areas

of families in regional areas

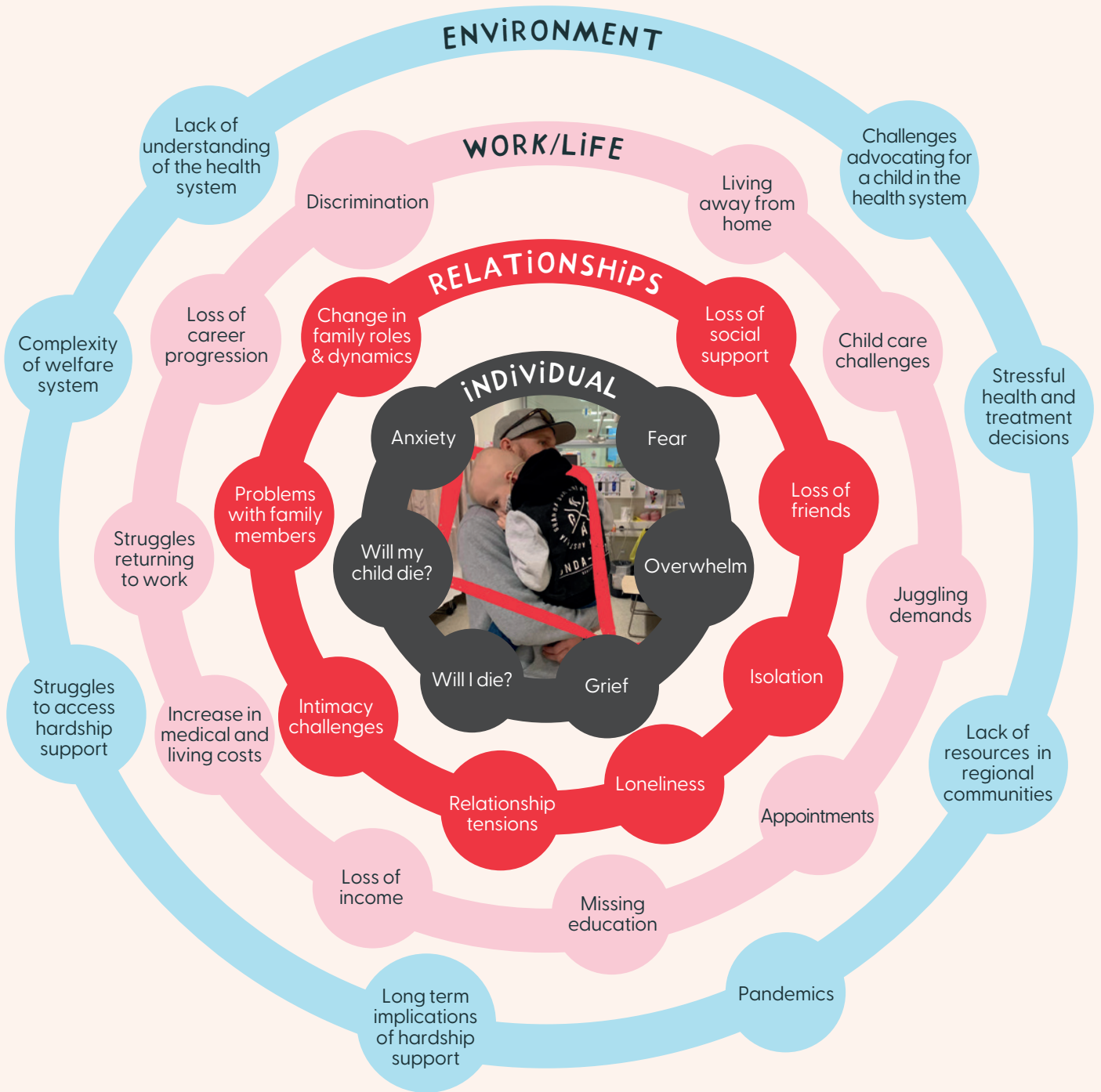
are struggling to find support to cope with anxiety and fear around a relapse.



**1 in 2 families**

had at least one parent living away from home.

**Childhood cancer is a complex trauma that affects every family member.** Its long-term nature and impact on almost every aspect of life means that it threatens the very survival of the family.





# Paediatric Cancer in Australia

## AN OVERVIEW

The Australian Institute of Health and Welfare estimates that in Australia in 2021, around 1,100 children (aged 0–18 years) will be diagnosed with cancer, equating to more than 90 children and teenagers diagnosed each month. There is usually no known cause for the diagnosis.

Thanks to significant advances in treatment, the five-year relative survival rate for children and teens with cancer aged 0–18 years is around 86% (Australian Institute of Health and Welfare, 2021). However, cancer and its treatment can continue to affect children and teenagers and families significantly even once treatment is complete. According to the Children's Cancer Institute, of those who do survive, two-thirds will have significant long-term treatment side effects, including organ dysfunction, neurocognitive deficits, impaired fertility, and secondary malignancies<sup>2</sup> (also known as 'late effects').

Behind these figures there are a wide range of survival rates for the many kinds of cancer that children and teens can be diagnosed with. For example, there has been little to no improvement in survival for several types of paediatric cancers over the last few decades, particularly hepatic tumours (Youlden et al., 2020). Limited treatment options may be available for some diagnoses, leading to a survival rate among children and teens that is relatively low. According to Cancer Council Queensland, cancer remains the leading cause of disease-related death in children over the age of one year<sup>3</sup>.

Based on analysis of Australian Childhood Cancer Registry data, the overall incidence rate of childhood cancer increased by 1.2% per year between 2005 and 2015 and is expected to rise a further 7% over the next 20 years to 2035 (Youlden et al., 2020).

While considerable focus goes into medical treatment, it is also critical to concentrate attention and support on the long-term wellbeing of the entire family. Cancer is a complex trauma that can affect families for many years and can have an impact on almost every aspect of life. Cancer puts each family member under extreme emotional pressure, challenges relationships, impacts career and education and threatens financial stability, in both the short and long-term.

Childhood cancer can threaten the very survival of the family itself.

Through our work, Redkite has seen this trauma manifest, and with the increasing paediatric cancer diagnoses and cure rates in Australia, more children, teenagers, and their families are living with the physical, mental and financial late effects of cancer.



2 <https://www.ccia.org.au/about-childhood-cancer>

3 <https://cancerqld.org.au/news/new-data-reveals-childhood-cancer-burden-australia/>

# Key Findings

# The greatest gaps in support are at end of treatment onwards and in bereavement - and those gaps are significant

Parents and carers reported high levels of need across all stages, and particularly at diagnosis and treatment. However, when asked about the degree to which their needs had been met, the biggest gaps came after end of treatment and in bereavement.

We know that a child's **diagnosis**, and the often long and traumatic **treatment** that follows, puts enormous pressure on families. There are many supports provided by hospitals and organisations like Redkite to help families through these challenging stages. The results show that, while there are still gaps in support during diagnosis and treatment, the highest needs of families were being met. A similar trend was found for needs during **palliative care**.

It is a different story at **end of treatment onwards** and in **bereavement**. Unfortunately, at these difficult stages of the cancer experience, some of the highest needs of families are least likely to be met.

## Leaving the safety of the hospital when treatment ends

We commonly hear from parents that leaving the hospital and returning home when treatment ends is one of the hardest transitions to cope with. While in the hospital, families have doctors, nurses and health professionals within reach and can readily access the support services that are located on or around the hospital grounds.

When treatment ends, families return home and the structure and accessibility of support that the hospital provides is no longer there and this reinforces the need for time and resources dedicated to smoothly transitioning families into community-based services that respond to the unique needs that families face.

“

*I think the trouble is that once you leave the hospital environment where it's so structured and organised, you can feel like you're in a little bit of a wasteland, and you just don't really know what to do next.*

- OLLIE

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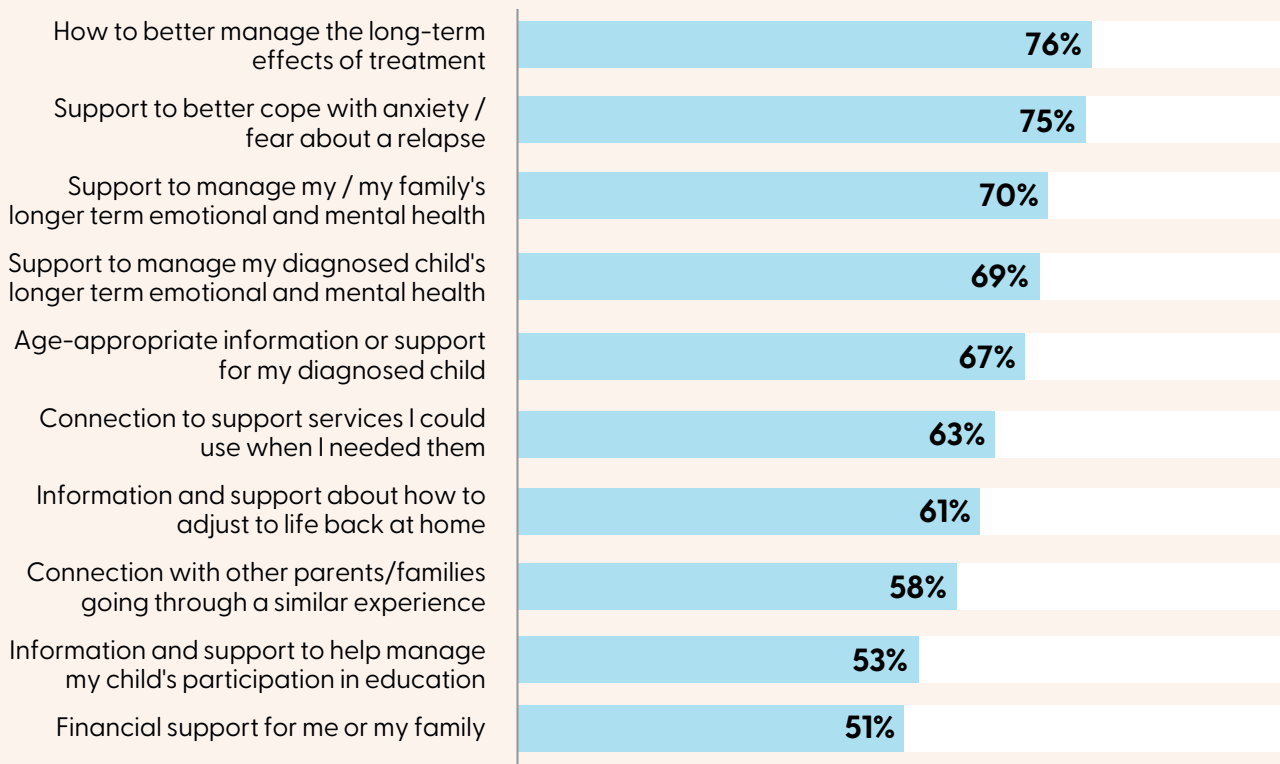
The results of the survey highlighted some concerning gaps in support after treatment ends.

**Managing the long-term effects of treatment, the entire family's emotional and mental health, and the anxiety and fear about a relapse, are significant areas of need that are not currently being met.**

There were also substantial differences among families where at least one person in the family had to live away from home during treatment. This highlights the challenging nature of families being separated from each other during treatment and that such separation can lead to additional needs for the family unit well into the future.

### Gaps in support from the end of treatment onwards

■ % Families with unmet needs (somewhat / mostly / completely unmet)



Refer to page 29 for the quadrant analysis maps of needs by the extent to which they were met. (Base: Between 231 and 246)

### Living with grief and loss

“

*With a lot of cancer support, it feels like the emphasis is on survival and treatment. You get to bereavement and it's like the journey is over. But for us, it's just beginning. I feel like I'm a fraud because I'm not on the journey anymore. But, I've still got a cancer journey, I'm just on a different one. It just feels like people expect that once the person has passed these services are not needed.*

– MEREDITH

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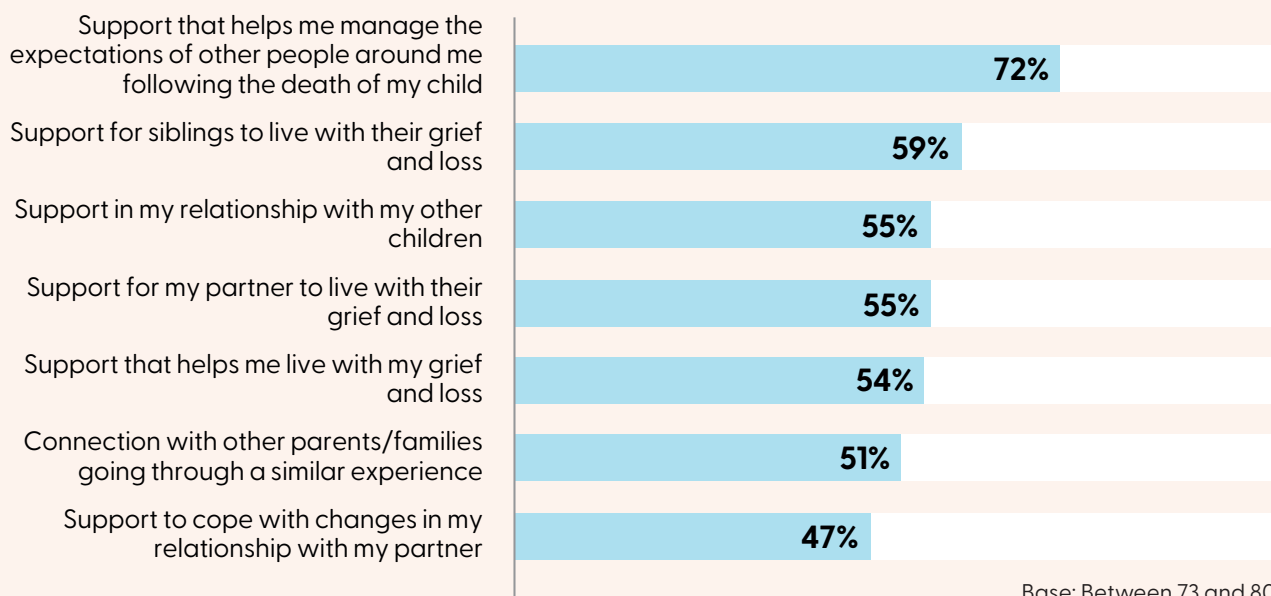
Grief doesn't have an end date. It is not a journey that has a conclusion and families need to learn to live with their grief and loss. Unfortunately, while parents have indicated that they and their family have a significant need for help with how to do this, it is where they are least likely to receive the specialised support they need.

The largest area where parents experience the lack of supports available is help in managing the expectations of other people around them after the death of their child. Not many people will understand what it is like to live with this grief and this lack of understanding from society has a marked impact on parents.

There were also a sizable proportion of parents who had gaps in support for siblings to live with their grief and loss, support in their relationship with their other children or support for their partner to live with their grief and loss.

### Gaps in support during bereavement

■ % Families with unmet needs (somewhat / mostly / completely unmet)



Base: Between 73 and 80

Refer to page 31 for the quadrant analysis maps of needs by the extent to which they were met.

“ I think bereavement services are necessary, but we should never underestimate the emotional needs throughout the whole cancer journey and beyond. People ask how I live with the pain. I explain it as a burning pain – it doesn’t go away. I accept that there will always be a part of me that is in pain. I will just function with it better or not.

– KATE



## CARIEN VAN WYK AND HER SON, JOSHUA

Joshua, Carien's only child, died from a brain tumour aged eight. There was limited psychosocial support for the family around making end-of-life decisions and home palliation. As new migrants, the family were isolated and had limited social networks. They didn't know what supports were available to them nor how they could access non-medical care for their son and themselves.

*"When the doctors confirmed that Joshua's cancer was back and this time it was terminal, it felt like the world was coming to an end. It was 2017, Joshua was six. There was no cure, but they gave us a few options. We could go back on intensive chemotherapy to prolong his life, but he would be sick and weak. We could give him chemotherapy pills at home to prolong his life, with fewer side effects. We could do nothing, and he would die.*

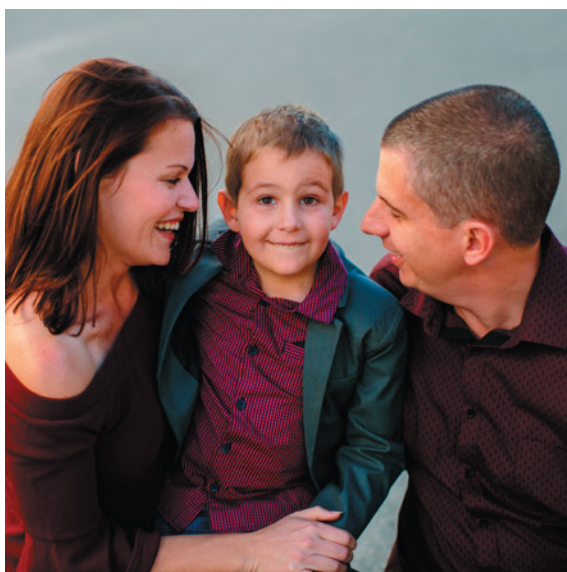
*It was such a shock because he had been healthy for 17 months and we weren't ready to let him go. We didn't want him to do the intense chemotherapy because it was not worth seeing him suffer when he was still going to pass away. So, we decided we would administer chemotherapy at home. We decided to prolong his life because we were not ready.*

*On Mother's Day 2018, Joshua refused to take his chemotherapy. We could see there were more bad things than good things coming from the chemotherapy. We wanted to stop*

*but that meant allowing him to die. I just didn't know what to do. I mean I could see in front of me that he was struggling. In February 2019, when nurses came and confirmed it was Joshua's last hours my husband Oscar, Joshua's dog Mango and I just laid with him and that's how he eventually gave his last breath.*

*Oscar was kind of over grieving when Joshua died because he did most of his grieving beforehand. I thought I was strong, but around the third month after Joshua passed I found myself in a big, big, big hole and I just knew I had to get out of there because I just couldn't cope with it anymore. It was hard because Oscar didn't understand my grief. I felt I had nothing to live for. I was a mum and then Joshua passed away. I'd been a mum at that stage for eight years, I didn't know how to be my old self before I had a child.*

*Oscar also got to the stage where he realised that we are grieving separately and in two different ways. He knows that he can't fix this for me, it's not something he can make better, no one can make this better. We struggled at a stage and I think we both thought we just can't be together, it's not going to work. But I'm so grateful that we got through it, and that we are together because that is what Joshua would have wanted. To see mummy and daddy being happy, with each other and living."*



## KEY FINDING #2

# There are clear gaps in emotional and mental health support across the whole family

The whole family feels the impact when a child is diagnosed with cancer. Mums, dads, carers, siblings, grandparents, aunts and uncles feel the stress and anxiety caused by the ripple effect that childhood cancer has across all aspects of their lives.

The survey confirms that there are significant gaps in support for the emotional and mental health needs of all family members. Those gaps are apparent across all stages of the cancer experience:



58% of families saying their emotional and mental health needs were not met at diagnosis and during treatment.



70% after treatment ends and beyond.

“

*I've seen a massive deficit in emotional and mental health support for children and their families and feel they need that scaffolding during treatment and afterwards, if and when they are 'well' again.*

– KYLIE

”

Emotional and mental health needs were strongly reflected throughout the comments made by participants in the survey:

“

*Both parents and older siblings have had significant mental health issues since treatment ended and there has not been a lot of support for this. There is still a huge fear of relapse and our daughter faces a very tough future... Our family is devastated by her diagnosis and I hate to think how we will cope if there is a relapse.*

– ANONYMOUS SURVEY RESPONSE

”

“

*PTSD and anxiety has been huge for almost all members of our family. We are struggling. My child's father had been off work due to PTSD/depression/anxiety and the eldest child is struggling with anxiety and problems at school. I have had very significant mental health issues and sought out help from a psychiatrist and psychologist as a result.*

– ANONYMOUS SURVEY RESPONSE

”

## TASH DJO AND HER SON, ROMAN

Tash, her husband and their two little boys, Vin and Roman, were living with her parents when Roman was diagnosed with acute lymphoblastic leukaemia. He was two-and-a-half years old. While it meant Tash had her family around her during Roman's treatment, it also meant its devastating impact was immediately felt by every family member.

*"It's hard. Ron and I were like ships passing in the night. Initially, Roman would only want me to stay with him at hospital, so I'd be at hospital with him and Ron would be at home with Vin. We could talk on the phone, or they'd come and visit and sometimes we'd swap and I go home with Vin. It was hard because we didn't get to see each other and have those normal chats, and normal family times. I think*

*Roman's longest stint in hospital was 19 days, but that could have been on the back of when he'd already been in hospital for 10 days.*

*Vin missed me too. We made an effort to make sure that he still felt included. If Roman wasn't wanting his dad to stay with him overnight, then I'd take Vin out during the day to try and keep that one-on-one time with him. It was hard, because I didn't want his whole world to turn into or have to focus on Roman because he's still a person as well.*

*My mum especially took it really hard. She was like, 'I've just got to soldier on and take each day as it comes'. My parents were great because if Roman got a fever and ended up in hospital again they would take Vin to preschool and pick him up. But it was hard."*





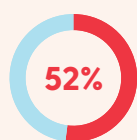
## There are significant gaps in emotional and mental health support for children living with cancer

The emotional and mental health impacts of cancer on children can be substantial. According to Steele et al., 2015 a sizable subset of young people with a childhood cancer diagnosis will “experience significant clinical levels of psychological distress at the time of diagnosis, during the course of treatment, and after treatment ends”. Children may experience fears of cancer recurrence, may find it challenging to re-integrate with their peers or school and they may experience concerns about changes to their physical appearance at treatment completion (Wakefield et al., 2010). A 2018 study investigated the levels of posttraumatic stress symptoms (PTSS) in children with cancer and found that 27% of childhood cancer patients indicated potential posttraumatic stress disorder ‘caseness’ (D’Urso et al., 2018).

“ I would love to have access to someone who specialises in childhood trauma, who understands the long-lasting effects of trauma and how that impacts children further on in their life. That would be so helpful.

– KYLIE

While our research demonstrates that all family members are impacted by the lack of emotional and mental health support that is uniquely tailored to their childhood cancer experience, data demonstrates that it’s especially true for diagnosed children themselves and particularly after treatment ends.



52% of parents believed their diagnosed child did not receive the emotional and mental health they needed at diagnosis and during treatment.



69% of parents believed their diagnosed child did not receive the emotional and mental health support they needed at end of treatment onwards.

The emotional and mental health needs of the diagnosed child was also one of the strongest themes in the comments from parents in the survey. Parents frequently commented on the difficulty of accessing appropriate emotional and mental health support for their diagnosed child; and some expressed concerns that they had seen their child experience significant longer term emotional and mental health impacts following a cancer diagnosis such as anxiety, behavioural issues and posttraumatic stress symptoms.

“ [Child] suffered recurring nightmares for about 12 months post treatment. There was no help from [the psychologist] at the treating hospital and seemed to be little support for his age elsewhere. We battled through on our own.

– ANONYMOUS SURVEY RESPONSE

## ANGELA MICKAN AND HER SON, HENRY

Angela and her husband Jack have three children: Natalie 12, Henry 11 and Bradley who is four. They live over an hour's drive from Adelaide. When she was 39 weeks pregnant with Bradley, Henry was diagnosed with leukaemia. Her family had to juggle life with a newborn, a very sick child and their sister who was waiting back home for them.

*Less than 48 hours after we received Henry's diagnosis and the day before he started treatment, I gave birth in Adelaide.*

*With a newborn to look after I couldn't be heavily involved in Henry's treatment. Because he was receiving chemotherapy I couldn't handle any waste, baths or showering. It just didn't make sense for me to stay in hospital with him. So, Jack stayed. It was very hard for me, but I couldn't give my full attention to both of them. I had to let Jack focus on Henry.*

*Natalie was eight at the time and staying with my mum and dad. It was important for her to keep a routine. I was so focused on having a newborn and what's going on with Henry, I wasn't around a lot for her in those first couple of months.*

*While on treatment, Henry was essentially away from school for a year and returned when he was eight. He's been off treatment for a year now and feels quite well in himself, but he's probably flatter than he would have been without receiving three years of chemotherapy and those emotionally intense periods.*

*Trying to get him back into a classroom with 20 other kids was huge. Initially the struggle was just getting him there. He didn't want to go, he'd feel sick. I think he was anxious that he would be sick at school. I really noticed the emotional support that he needed going back to school. So, my sister-in-law or I would stay with him the whole time he was at school. Sometimes I would be breastfeeding in the staffroom because I had a baby.*

*This went on for a full school term.*

*His teacher would let the kids in the class wear their caps in the classroom which you normally couldn't do. But he would allow it because Henry wouldn't let anybody see him without*

*a hat or a beanie. He didn't worry about wearing it at home, it was more the school environment. At school, there was no way anyone was going to see him without his hair!*

*So going back to school was a huge mental load because he had to think, and he had to use his brain and he had to look at people and interact with people. I found he also initially struggled with whole-class instruction, he needed one-on-one support. So, by having either myself or my sister-in-law there, the teacher would say, "All right, everybody, I need you to do this" and we would then relay that to him.*

*It was hard, because you've got this massive role of helping a kid who's been really, really sick – and had his life totally disrupted – to transition from an artificial environment of hospital and treatment back to 'normal life'.*

*Normal life like going to school, eating veggies, doing homework and sharing things with your sister.*



## There is a lack of information and support for siblings

“ My son misses his brother. His brother was his little sidekick. My daughter has never cried, she never went to the funeral, she never talks about him. She doesn't want to have a lot to do with me. I don't know whether she blames me for not being able to fix her little brother, or for allowing him to suffer, or the fact that I wasn't there when she needed me. I've heard a few people say, it's because I'm her safe person that she feels she can act out to me, but it doesn't make it any easier.

– MEREDITH

”

Through Redkite's support of families for almost 40 years, we know that a childhood cancer diagnosis can substantially affect the brothers and sisters of a diagnosed child. Siblings may feel that their family as a whole had been ripped apart by the cancer (Schoors et al., 2019) or they may feel 'invisible' within the family unit and display higher levels of psychological distress (Patterson et al., 2015). In D'Urso et al's 2018 study of children with cancer and their siblings, siblings were found to have relatively high rates of posttraumatic stress symptoms and a similar level of potential posttraumatic stress disorder to that observed among children diagnosed with cancer.

“ Cameron came to visit on their birthday [they are twins] and Tom was not well. He'd just started radiation and was slowly getting his vision back, but he still couldn't talk. So, it was tough for Cam. Tom was such a different brother than what Cam was used to. Normally, they were very close, but Cam became impatient and wanted to know if Tom was fixed yet.

– TRISH

”

In households where the diagnosed child had another sibling living at home, a high proportion of parents and carers struggled to find information and support for siblings across the different stages of their experience with childhood cancer:

### Families with gaps in information and support for siblings



\*Some variation in sample size for each stage of cancer, as follows: Diagnosis and on treatment n=414; End of treatment onwards n=188; Palliative n=51; Bereaved n=58.\*

“ On his birthday we always take a walk as a family and one of the boys always has to have a fight with us. It's a hard day because what do you do with the death of a young person? A brother that they absolutely adored was struck down. They were three and now they're two.

– KATE

”

## NICKY SHERLOCK AND HER CHILDREN

The Sherlock family are a blended family made up of parents Nicky and Les, and kids Brianna (15), Jess (14), Riley (13) and Jamie (4). The family live on a small farm in rural Western Australia which they share with various animals including chooks and sheep. In September 2019, their farm life changed overnight when Jamie was diagnosed with leukaemia.

*Jamie's diagnosis was the beginning of a pretty stressful time for us all. Because we live so far from the hospital Jamie wasn't allowed to go home. So, I stayed with him while my husband kept working to pay the bills.*

*Brianna and Riley came to see Jamie whenever they could while juggling schoolwork and being mindful of Jamie's vulnerability. I had to send my daughter Jess to my parents so she was looked after by them for 12 months.*

*Mum and dad would bring Jess up whenever they could even though it is a few hours' drive each way. Jess actually missed a lot of high school, but she is a real trooper. Jamie's treatment was really tough on Jess and she still has issues with schooling and things but we're trying to work through them.*

*It was a lot of separation. It was a stressful time. I don't think I felt grass under my feet for twelve months and COVID-19 just made things massively harder for the family.*

*When the kids were isolated from school, I home-schooled Jess up in Perth because I didn't want mum to have that stress. That was extremely stressful. Probably the worst decision. But at least I got to have both my kids there and I had my sister come and stay with us when I had to be at the hospital, so Jess would have someone with her all the time.*



## KEY FINDING #5

# There is a need for greater connection with other families

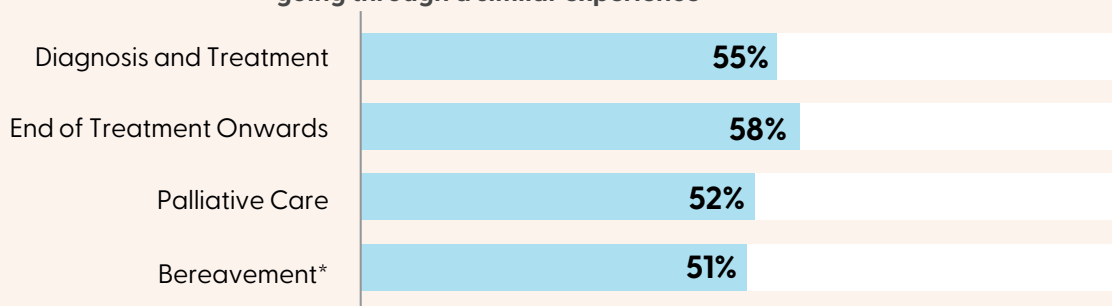
The research also highlighted that across different stages of childhood cancer, parents and carers are keen to connect with other families going through a similar experience.

“ I was going to bed crying, because I didn't want to put any pressure on the kids. I was going to be a rock for them – but inside, I was breaking away. I then joined a (Redkite) Dads Connect group. It was good to catch up with others in the same situation. I was keeping a lot of things inside. Now, I have learned to speak more.

– KARL

Parents reported they were missing out on connection with other parents and families consistently, regardless of where they were in their experience with childhood cancer:

### Families with gaps in need to connect with other parents/families going through a similar experience



\*Some variation in sample size for each stage of cancer, as follows: Diagnosis and on treatment n=602; End of treatment onwards n=240; Palliative n=61; Bereaved n=73.

A lack of connection with other families was described by some parents in the survey as both isolating and lonely. Other parents, reflecting on their child's experience, made comments around never feeling truly understood by others, further emphasising the importance of peer support from families who've been through a similar experience.

“ In helping Finley face death, I muddled through by doing my own research. But what I really wanted was someone to tell me what to do. I wanted someone who had walked this road with other families to talk it through with me, to guide me towards resources. I was not aware of Redkite at the time.

– KATE

(A gap was) definitely not being connected with anyone else whose child was going through or had been through the same cancer diagnosis and treatment. I felt very isolated, alone and disconnected.

– ANONYMOUS RESPONSE FROM THE SURVEY

## TRISH CARPENTER AND HER SON, TOM

Trish has identical twin boys, Thomas and Cameron. Thomas was diagnosed with medulloblastoma in December 2017 when the boys were almost seven. He died 13 months after diagnosis on 9 January 2019. Their birthday was 11 days later, when Tom would have turned eight and Cam did turn eight.

*We'd been through it for 11 months by the time the relapse and the terminal prognosis came. I would've loved information from parents on what they had done when dealing with the palliative care scenario.*

*I have a great support network but some people who support bereaved parents don't quite understand our need to talk to other grieving parents because they think that we're taking on their pain. It's logical to think that it compounds the sadness, but that's not the way it works. I think it's validation that other people have been in the same position.*

*We all grieve differently. My husband, Owen is grieving and Cam is grieving too. When I talk to other bereaved mums and fathers, I don't understand why, but I always feel lighter at the end.*

*Whether we've had a cry or we've laughed, having those shared experiences really connects you. It's kind of like you're in this club, but no one wants to be in this club and you can't escape membership. Once you're in, you're in.*

*It's like you're in the football club and you love that team and you're connected to all those people who love that team.*

*We're all connected by this very same grief. I'll always be a little bit broken and sometimes you just want to find the other broken people so you don't feel so alone.*



## There are some groups that experience greater gaps in support than others

Our survey also found some groups were more likely to experience gaps in support than others:

### When a diagnosed child has relapsed

Experiencing a relapse can feel like a ‘second hit’ for parents who are already living with childhood cancer and can make them more vulnerable to experiencing significant trauma and distress (Jurbergs et al., 2009). One in five parents in the survey reported that their child had experienced a relapse. These respondents were more likely to report significantly greater gaps in support at diagnosis and during treatment as well as at end of treatment onwards.

### When someone has to live away from home

For around half of the parents surveyed (48%), at least one parent in the family had to live away from home during treatment. We know this can put additional practical, financial and emotional strain on families. We found that these parents were more likely to report significant gaps in support across a large range of need domains, when compared to those where no-one had had to live away from home.

“ I think we had two days’ notice that we had to go to Melbourne [from Tasmania]. At that stage we’d only been given snippets of what the treatment would look like and how long it would take, so when they said this is going to be a year, straight away your brain goes, “I haven’t got enough leave.”

– IAN

### Regional and remote families

Living in a regional or remote location can lead to real difficulties in accessing services, including psychosocial services (Watts et al., 2016). Just over a third of respondents in the survey were living in a regional or remote location at the time of diagnosis. There were some needs that were more likely to be reported by regional or remote families than by families living in metro areas. For example, for families living in a regional or remote location at the time of diagnosis, 82% reported significant gaps in support at end of treatment to better cope with anxiety and fear about relapse, compared to 71% of families living in metro areas.

### Mums

During diagnosis and treatment, mums responding to the survey<sup>4</sup> were significantly more likely to report that a range of key needs were unmet. 60% of mums said they didn’t get the support they needed to manage their or their family’s emotional and mental health needs, compared to 47% of dads or other carers.

Likewise, bereaved mums had significantly higher levels of gaps in support compared to other parents at this stage. This was particularly in terms of the need for support in their relationship with their other children and for support that helps them live with their grief and loss.

<sup>4</sup> Around 85% of the survey respondents were mums and 14% were dads (the remainder were other carers/ guardians/ support persons).

## Aboriginal and Torres Strait Islander Families

Whilst there is little research specifically identifying the gaps in support for Aboriginal and Torres Strait Islander families who have a child with cancer, research by Rotte, et. al. (2013) highlighted the factors that may influence poorer outcomes in families including:

- Displacement - for example, language barriers, lack of culturally appropriate accommodation and dislocation from family support and country
- Socio-cultural factors – for example, communication issues, education levels and understanding complex health issues, financial disadvantage and strong cultural beliefs
- Geographical barriers – for example, unavailable diagnostic facilities, later diagnosis and shorter follow up





# Moving Beyond Medicine:

**Redkite's Solution to the  
Hidden Health Crisis**

# Moving Beyond Medicine:

## REDKITE'S SOLUTION TO THE HIDDEN HEALTH CRISIS

It's clear from our research that there are significant gaps in support across the entire cancer experience that urgently need to be addressed for children with cancer and their families. It is also clear that there is insufficient resourcing for the psychosocial care of families in both the health and community sectors.

Redkite already provides emotional and mental health support for families throughout their experience of cancer, including through our own community social work team and by funding social workers in hospitals across Australia to support families throughout their treatment. The results of this research have reinforced our ambitious vision to scale up and diversify those supports, which up until now have predominantly been focussed on parents. We are committed alongside our partners in the health and community sectors, to ensuring the whole family gets the support they need when they need it. For Redkite, early intervention will be critical to our expanded support program, in addition to heightened and accessible support when back at home and in the community.

Following are key recommendations being made by Redkite that expand our current family support services that will make significant contributions to closing the urgent gaps in support identified by this research. These programs are also well aligned to the recommendations of the National Children's Mental Health and Wellbeing Strategy.



**In hospital**

**Transition home**



**At home & in the community**

### **Family Wellbeing & Transition Program**

A program that operates within all paediatric oncology wards and delivered by dedicated Redkite positions on ward. Their role is to improve the wellbeing of families and support the early intervention and prevention of emotional and mental health issues. They will equip families with the tools and resources they need for their mental health and wellbeing while in hospital and prepare them for transition home such as connecting them to services in the community, including Redkite's specialist community social work team.

### **Family Mental Health & Wellbeing Program**

A community-based program tailored to reducing the impacts of childhood cancer on the entire family, including specialised support for children (diagnosed child and siblings). It will be a stepped-care model of support starting with prevention and early intervention through to targeted and more intensive support for families with complex needs.

This will include tailored support for Indigenous families and those who are culturally and linguistically diverse, developed and delivered in partnership with their communities and other expert service providers.

### **Peer Support Program**

A peer support and mentoring program connecting family members and empowering them to support each other.

The program will include expanding Redkite's current facilitated groups and establishing one-on-one peer support and a lived-experience mentor program.

# Appendix

# Methodology

The purpose of this research was to better understand the non-medical, psychosocial support needs and gaps for families living with paediatric cancer. We wanted to understand families' needs throughout their experience of cancer, including at:

- diagnosis and treatment
- palliative care
- bereavement
- end of treatment onwards

Importantly, we wanted to know and quantify:

- what proportion of families experienced those needs
- how severe those needs were
- to what degree they were met

The findings were intended to help Redkite focus on tackling the most significant gaps in support experienced by families, both in our own services and through advocating for greater funding to help better meet the needs of families.

The survey approach was adapted from a needs assessment model developed by the Australian Institute of Family Studies (Smart, 2019) which draws on common practice in the social services and public health sectors. A desktop review of existing needs assessment tools in paediatric and young adult cancer helped inform the needs included in the survey, and an Advisory Group of people with lived experience of paediatric cancer provided important context and input across the research.

Data on the needs of families was sought through an online survey of parents and carers of a child aged 0-18 years diagnosed with cancer, which included parents and carers of a child (currently aged 0-18 years) and bereaved parents and carers (whose child died when they were aged 0-18 years). The sample was drawn from Redkite's client database and therefore reflects the needs of families who have received support from Redkite rather than all families impacted by paediatric cancer. The survey sample broadly reflects the state and territory distribution of cancer diagnoses in Australia (Australian Institute of Health and Welfare, 2021) and has good representation across the 0-18 age group<sup>5</sup>.

To ensure we gathered data on the range of needs families have throughout their whole experience, we surveyed parents and carers whose child had been diagnosed up to 10 years previously – importantly, this ensured that we had a large enough group of families who had finished treatment to understand the longer-term needs of families.<sup>6</sup>

The survey was conducted between 28 September and 19 October 2020. A total of 3,578 parents were invited to participate with 713 responses received, representing a 20% response rate. The demographic breakdown was:

- Parents and carers living in regional and remote areas of Australia n=188
- Bereaved parents and carers n=100
- Dads n=97
- Families where a child has relapsed n=140
- Families where another language is spoken at home n=103
- Families where someone in the family had to relocate for treatment n=255

<sup>5</sup> The child's age at diagnosis within the sample was as follows: 41% 0-4 years; 28% 5-9 years; 19% 10-14 years and 12% 15-18 years.

<sup>6</sup> Sample size for respondents who experienced each cancer stage was as follows: Diagnosis and treatment (n=604-644); End of treatment and onwards (n=249-255); Palliative (n=72-75); Bereavement (n=79-82).

# Identifying Gaps in Support:

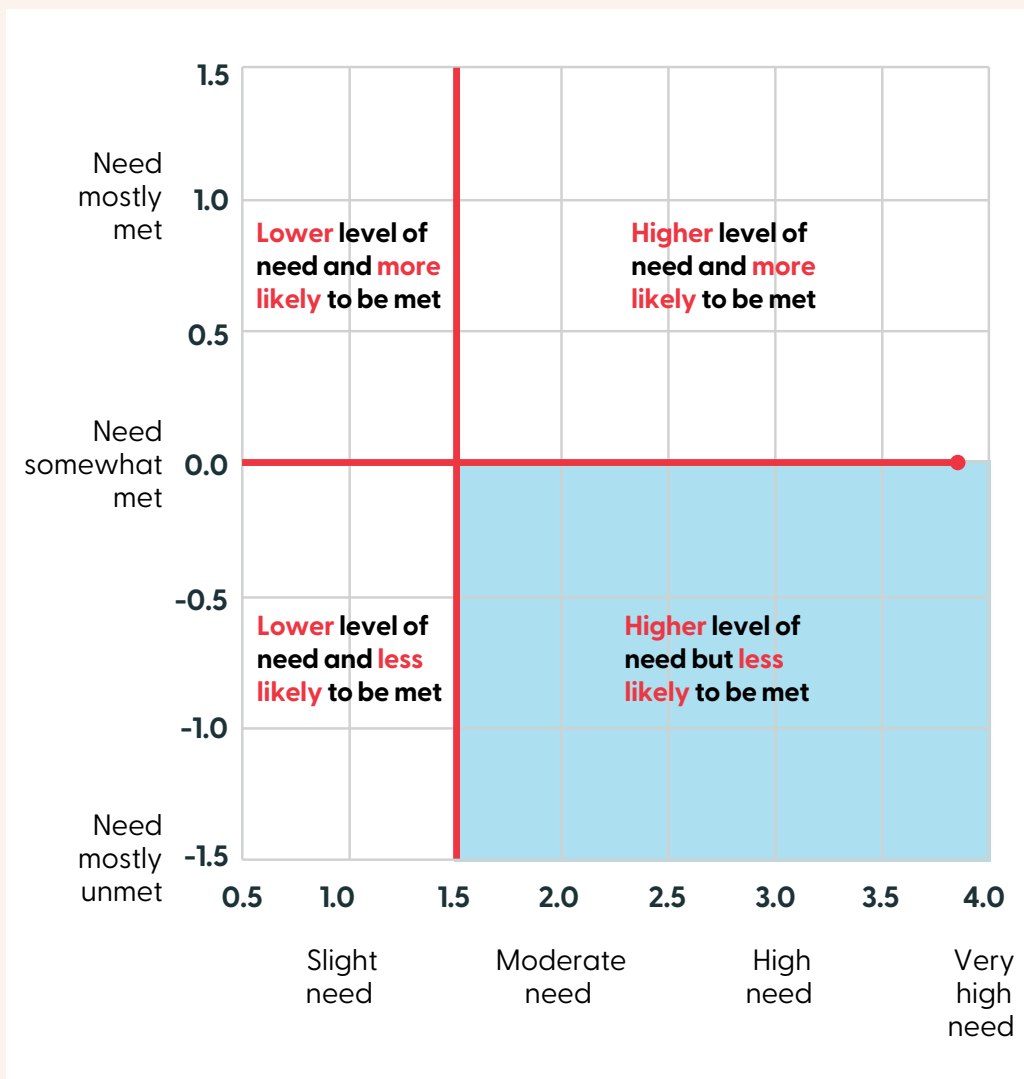
## QUADRANT ANALYSIS MAPS

This analysis examining the importance of needs by the extent to which they were met (Figures 6 to 9 below) was conducted by mapping mean scores. That is, the mean scores for each type of need were mapped in terms of the 'level of need' (i.e., on a five-point scale where 'no need/NA' = 0 and 'very high need' = 5) and the 'degree to which the need was met' (i.e., on a five-point scale where 'completely unmet' = -2 and 'completely met' = 2). This scale can be seen in Figure 5 below. This quadrant mapping analysis has been conducted for each stage of the childhood cancer experience covered in the survey.

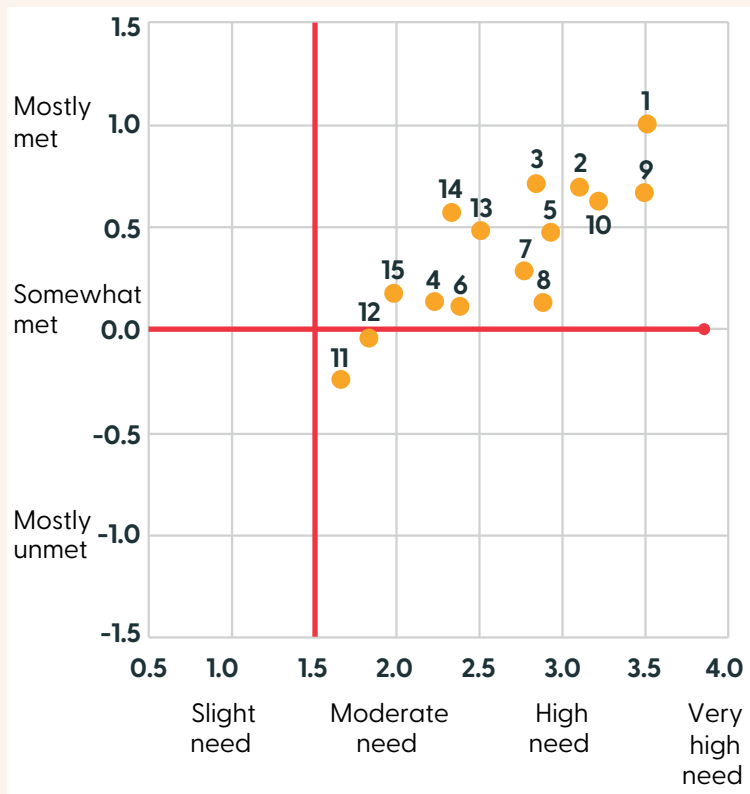
It is important to note the following in the interpretation of these charts:

- The further a data point is positioned to the right, the higher the level of need among parents
- The closer a data point is positioned to the top, the more likely a need is being met
- Larger gaps in need are positioned in the bottom right quadrant of each map (or 'quad plot'). That is, needs positioned in this quadrant are likely to be sizable and less likely to be met.

**Figure 5: Example chart for mapping needs**

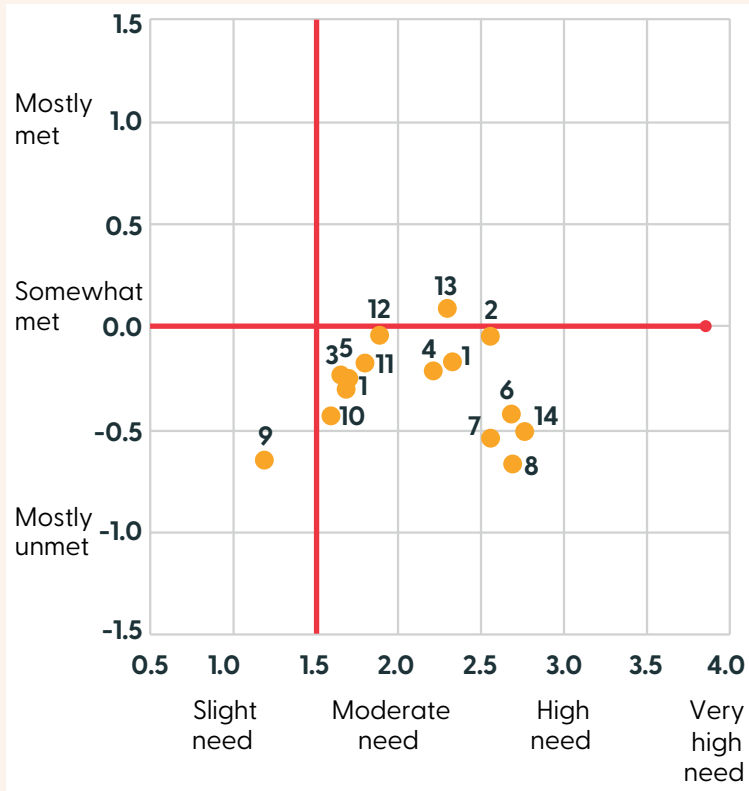


## Needs - Diagnosis and treatment



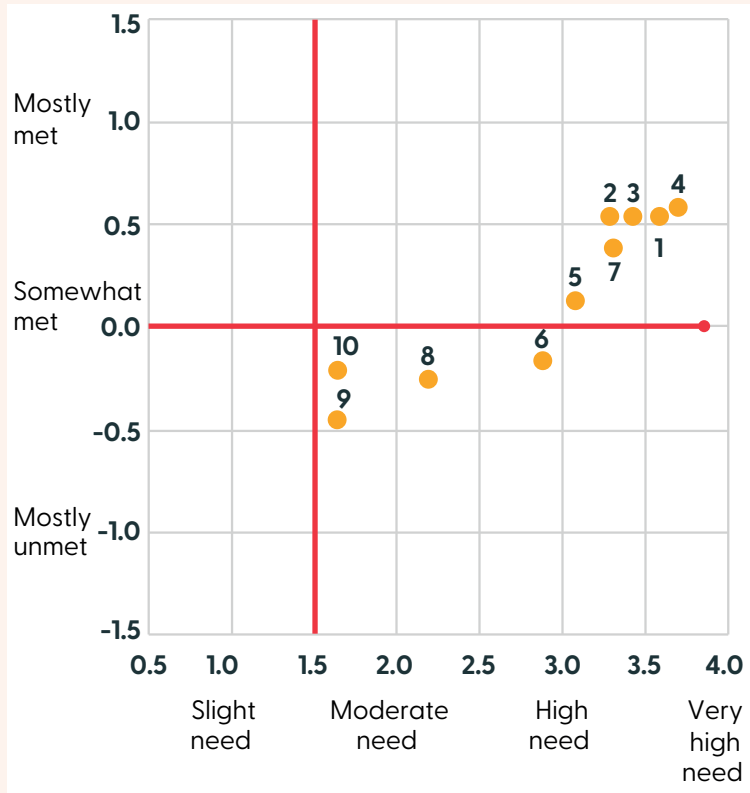
- 1 Access to quality / trusted information
- 2 To know who else I could contact for support
- 3 Someone to help me understand and navigate the hospital / health system
- 4 Connection with other parents/ families going through a similar experience
- 5 Age-appropriate information or support for my diagnosed child
- 6 Information or support for siblings
- 7 Support to manage my diagnosed child's emotional and mental health
- 8 Support to manage my / my family's emotional and mental health
- 9 Practical support (e.g. parking permit, transport, accommodation, accessing Centrelink, support with my employer)
- 10 Financial support for me or my family
- 11 Support to cope with changes in my relationship with my partner
- 12 Support to help manage my child's friendship changes / issues
- 13 Support with my child's diet and nutrition needs
- 14 Information and support to help manage my child's engagement in education
- 15 Information and support to help understand my child's fertility options

## Needs – End of treatment onwards



- 1** Information and support about how to adjust to life back at home
- 2** Connection to support services I could use when I needed them
- 3** Connection with other parents/families going through a similar experience
- 4** Age-appropriate information or support for my diagnosed child
- 5** Information or support for siblings
- 6** Support to manage my diagnosed child's longer term emotional and mental health
- 7** Support to manage my / my family's longer term emotional and mental health
- 8** Support to better cope with anxiety / fear about a relapse
- 9** Support to cope with changes in my relationship with my partner
- 10** Support to help manage my child's friendship changes / issues
- 11** Support with my child's diet and nutrition needs
- 12** Financial support for me or my family
- 13** Information and support to help manage my child's participation in education
- 14** How to better manage the long-term effects of treatment

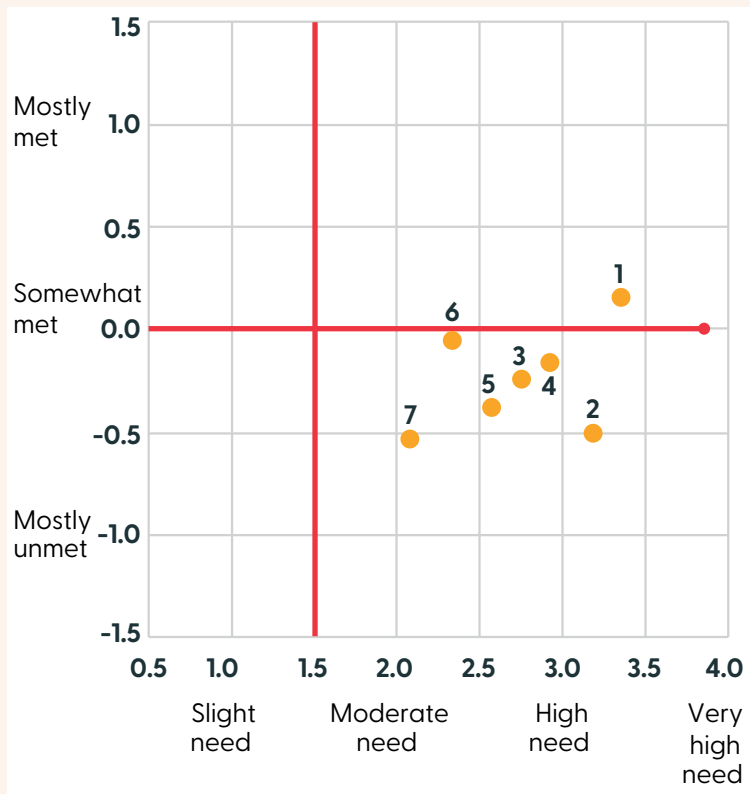
## Needs – Palliative care



- 1** Information and support to help make important decisions affecting my child
- 2** Connection to support services I could use when I needed them
- 3** Support to make positive memories with my child
- 4** Support to focus on my child's quality of life as much as possible
- 5** Age-appropriate information or support for my diagnosed child
- 6** Information or support for siblings
- 7** Financial support for me or my family
- 8** Connection with other parents/families going through a similar experience
- 9** Support to cope with changes in my relationship with my partner
- 10** Support to help manage my child's friendship changes / issues



## Gaps in support – Bereavement



- 1 Support that helps me live with my grief and loss
- 2 Support that helps me manage the expectations of other people around me following the death of my child
- 3 Support for my partner to live with their grief and loss
- 4 Support for siblings to live with their grief and loss
- 5 Support in my relationship with my other children
- 6 Connection with other parents/families going through a similar experience
- 7 Support to cope with changes in my relationship with my partner

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Redkite acknowledges the Traditional Owners of the land throughout Australia, and their connections to land, waters and community. We acknowledge their stories, traditions and living cultures, and we pay our respect to Elders past, present and emerging.

Redkite is committed to ongoing learning about the individual needs of our families. We strive to create a respectful and inclusive space for people of all cultures and identities.





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