



2022-23

Pre-Budget Submission

Dear Minister Sukkar,

Re: Redkite 2022-23 Pre-Budget Submission

On behalf of Redkite, we welcome the opportunity to make a pre-budget submission to inform the 2022-23 Federal Budget.

Redkite is Australia's only national children's cancer service provider, supporting families for almost 40 years with psychosocial support no matter where they live in Australia, at all stages of their child's long and uncertain cancer journey. From diagnosis, throughout treatment and whatever happens when treatment ends, Redkite is there for families whenever and wherever they need us.

On 6 October 2021, Redkite launched the results of its recent national family needs survey in a report titled ***The Hidden Health Crisis – Childhood Cancer Needs More Than Medicine***. The report provides a sobering snapshot into significant gaps that still exist in support available to families going through childhood cancer.

Five significant areas for concern were identified:

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

Moving Beyond Medicine: Redkite's Solution to the Hidden Health Crisis

Our 2022-23 Pre-Budget Submission outlines a national mental health and wellbeing initiative that aims to close the gap for parents, diagnosed children and their siblings who require significant emotional and mental health support at the end of hospital treatment.

Wellbeing and Community Transition program

8 Family Wellbeing and Transition Coordinator positions to support children and families with transition from hospital to home, focused on prevention and early intervention of cancer impacts on mental health and wellbeing of all family members.

Specialist paediatric oncology community mental health and wellbeing program

8 Mental Health and Wellbeing Community Social Workers will operate in the community to support families when they return home from the hospital, focused on minimising impacts of cancer on mental health and well being of each family member.

Specialist paediatric oncology community indigenous support program

Establish a new oncology-specific community-based service for Aboriginal and Torres Strait Islander (ATSI) families in partnership with Indigenous communities & health organisations. The program will involve funding for two dedicated positions for ATSI Liaison officers.

Peer support and mentor program

Establish facilitated group and individual peer support programs addressing families need for connection.

Kind regards,



Monique Keighery, CEO

The Hidden Health Crisis

Children's cancer needs more than medicine

Right now, we estimate that **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.

On 6 October 2021, Redkite launched the results of our recent national family needs survey in a report titled *The Hidden Health Crisis – Children's Cancer Needs More Than Medicine*.

The report provides a sobering snapshot into significant gaps that still exist in support available to families going through childhood cancer. In Australia, 90 children a month are diagnosed with cancer. The immediate and ongoing core focus is on medical survival for these kids and families. The non-medical impacts of cancer and the extreme pressure that childhood cancer puts on each family member is not often talked about.

Last year, Redkite conducted a national family needs survey to quantify the size of the problem. In total, 713 parents and carers of a child (aged 0-18 years) diagnosed with cancer between 2010 and 2020 responded to the survey.

Key Survey Findings

While there are gaps in support throughout the entire cancer experience, **the greatest gaps in support are after treatment ends** once families leave the hospital and return to the community.



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

Support is lacking for the emotional and mental health of the **child living with cancer...**



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 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**

There is a need for greater connection with other families



families report a lack of connection with other families at the end of treatment

Families were at an even greater 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

Now, more than ever, this situation cannot remain hidden. We need to shine a light on it, change the narrative around childhood cancer and stand up for the non-medical needs of these kids and their families. Redkite is committed to lead change on how holistic support is provided and securing support to implement solutions.

Use QR code to download your copy of Redkite' report
The Hidden Health Crisis



Redkite

A lifeline for families facing childhood cancer

When a child is diagnosed with cancer, it affects the whole family. The medical system is not designed to address the complex psychosocial challenges that are unique to childhood cancer and impact the wellbeing of each family member long after the hospital treatment ends.

Redkite is the only national non for profit with nearly 40 years of experience in holistic psychosocial support. Critical mental health and wellbeing care is provided, alongside financial assistance, support resources a child and their family will need throughout the long and traumatic cancer experience.

Redkite supports over 3,000 individuals every year with the practical, mental health and financial support to help families find their strength to keep going in the face of their child's cancer, including:

- **Hospital-based support** - Redkite is the largest non-government funder of hospital-based social workers and music therapists in children's cancer wards in Australia. Currently funds 9 social workers and 9 music therapists; over \$9.5M funding into hospitals for these roles over past seven years – more than \$1.3M in 2020 alone.
- **Support when families leave hospital** - Redkite provides free, specialised psychosocial and practical support to children with cancer and their families to ensure support outside of the hospital environment at a time they report feeling particularly isolated, anxious and overwhelmed.

This is all the more important for regional and rural families - 25% of diagnosed families and bereaved families - approximately 3 children die per week in Australia from childhood cancer.

- **Financial assistance** – The largest and most comprehensive program of its kind in Australia for families facing their children's cancer - over \$2M last year in direct financial assistance, Redkite helps families cover essential living costs such as fuel, food and utilities.

COVID-19 had a significant effect on families that we support, with demand levels soaring by 36% in 2020 compared to 2019 levels. The virus presented a significant threat to the health of immunocompromised children and increased levels of anxiety and stress for families. Throughout the lockdown, Redkite was one of the very few charities that continued to operate in hospitals, with the rest of our support provided via online channels.

Moving Beyond Medicine: Redkite's Solution to the Hidden Health Crisis

Building Resilient Families Through Cancer and Beyond

This is a national mental health and wellbeing initiative proposed by Redkite that over the next six years aims to close the gap for parents, diagnosed children and their siblings who require significant emotional and mental health support at the end of hospital treatment. The initiative will be delivered through several programs.

Redkite is already successfully delivering two components of this program in NSW, improving emotional and mental health support to families when they transition from treatment in hospital to home.

Wellbeing and Community Transition Program

New Family Wellbeing and Transition Coordinator positions to support families while in hospital, assisting them in transition home. These coordinators will address mental health and wellbeing of the families, with proactive referrals to Redkite's specialist community mental health and wellbeing program.

- Eight dedicated Family Wellbeing and Transition Coordinator positions.
- Early intervention and proactive support for families in hospitals through mental health and wellbeing programs delivered via various channels, including digital, on the phone and in person support.
- Tailored transition support plans, proactively preparing families for when they return home with proactive follow up.
- Proactive referral to Redkite for mental health and wellbeing support team when families transition home from the hospital

Program cost: \$9m over six years

Cost per year:

Y1 - \$990,314; Y2 - \$1,265,500; Y3 - \$1,483,600; Y4 - \$1,674,500; Y5 - \$1,783,400; Y6 - \$1,811,700

Deliverables:

- Establish eight dedicated Family Wellbeing and Transition Coordinator positions
- By year 3: 2,000 families supported; by year 6: 5,000 families supported

Outcomes:

- Emotional and mental wellbeing - ensuring children with cancer, and their families are better able to manage their emotional wellbeing and mental health (e.g. feeling heard and understood - at least 75% of people supported by Redkite Family Wellbeing Transition program feel this way).
- Empowerment - ensuring families are confident and equipped to navigate the impacts of childhood cancer (e.g. information and knowledge to navigate childhood cancer - at least 85% of people

<ul style="list-style-type: none"> 70% of all families (3900) have transition plan in place 	<p>supported by Redkite Family Wellbeing Transition program feel this way).</p> <ul style="list-style-type: none"> Connection - enabling families to have meaningful connections throughout their child's cancer experience (e.g. feeling less alone, feeling more connected to organisations that can help - at least 75% of people supported by Redkite Family Wellbeing Transition program feel this way).
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Funding includes ongoing outcomes measurement for this program, inclusive service delivery, ongoing best practice development and improving social supports around the family.

Specialist Paediatric Oncology Community Mental Health and Wellbeing Program

Establish eight Mental Health and Wellbeing Community Social Workers, specialising in paediatric oncology, who will operate in the community to support families in the community and when they return home from the hospital. This program will run in partnership with Wellbeing and Community Transition Program as well as other specialist providers in the sector to deliver:

- Tailored wellbeing and mental health support available to all family members when they return home from the hospital, including parents, children and close family members
- Specialised, paediatric oncology-specific support at any stage of the cancer experience, inc. palliative and bereavement, provided by experts in the paediatric oncology space.
- Support is available across multiple channels to be accessible to all families, including in-person, online and phone
- Stepped-care model of support starting with prevention and early intervention through to targeted and high-level interventions with complex support coordination

The services will be delivered utilising face to face, phone, online video conferencing and digital channels and will be focussed on the following steps:

- Prevention** - Self-led and low intensity professional interventions proactively offered and related to skills and resilience building, psychoeducation and coaching, proactive identification of predictable (evidence based) risks to well-being and mental health in the short, medium and longer term and delivery of risk-mitigation strategies for wellbeing.
- Early intervention** - low to moderate intensity counselling, resource provision, and other specialist psychosocial support to address risk factors and actual challenges arising related to adjustment to cancer and well-being and mental health in the context of cancer.
- Targeted intervention** - moderate level psychosocial support related to risk factors, actual problems, distress and/or mild to moderate mental illness. This can include mental illness focussed work with each person, delivered by a mental illness specialist social worker alone or in co-work with other community-based oncology social workers; referrals or co-work and case management work with external agencies; advocacy and facilitation of access to appropriate services
- High level intervention** - direct work focused on the identified issues; formal referrals to external agencies for severe mental illness or situations with high risk factors; ongoing co-work with the external services; case management where required.

Program cost: \$8.9m over six years

Cost per year:

Y1 - \$1,148,920; Y2 - \$1,202,100; Y3 - \$1,406,300; Y4 - \$1,637,400; Y5 - \$1,751,500; Y6 - \$1,774,700

Deliverables:

- Establish 8 new positions of Mental Health and Wellbeing Community Social Workers
- By year 3: 2,600 individuals supported;
By year 6: 3,400 individuals supported

Outcomes:

- **Emotional and mental wellbeing** - children with cancer and their families are better able to manage their emotional and mental health when they return home from hospital (e.g. reduced stress and distress, reduced anxiety - at least 80% of people supported by specialist service feel this way).
- **Empowerment** - ensuring families are confident and equipped to navigate the impacts of childhood cancer (e.g. skills and resources to better support themselves and their family, recognising and using strengths, belief in self to face challenges - at least 80% of people supported by specialist service feel this way after a period of consistent support e.g. 6+ months).

Funding includes ongoing outcomes measurement for this program, inclusive service delivery, ongoing best practice development and improving social supports around the family.

Specialist Paediatric Oncology Community Indigenous Support Program

Establish a new oncology-specific community-based service for Aboriginal and Torres Strait Islander (ATSI) families in partnership with Indigenous communities & health organisations. The program will involve funding for two dedicated positions for community based ATSI Liaison officers and will deliver:

- Resources and programs developed to better support families return to their communities
- Community based mental health and wellbeing support co-designed and delivered to ATSI families in partnership with their communities and ATSI specialist support organisations in culturally appropriate way and settings
- Support at any stage of the cancer experience, including in collaboration with existing hospital based ATSI liaison officers, and across palliative and bereavement stages as appropriate

Program cost: \$3.5m over six years

Cost per year:

Y1 - \$375,812; Y2 - \$599,950; Y3 - \$604,620; Y4 - \$624,920; Y5 - \$669,860; Y6 - \$679,030

Deliverables:

- By year 3 - Pilot the program and resources with select communities
- By year 6 – Increased access to new Redkite services for ATSI families

Outcomes:

- **Connection** - ATSI families have meaningful connections throughout their child's cancer experience (e.g. connected to organisations that can help - at least 75% of ATSI families feel this way).
- **Empowerment** - ATSI families are confident and equipped to navigate the impacts of childhood cancer (e.g. information and knowledge to navigate childhood cancer - at least 75% of ATSI families feel this way).

- **Emotional and mental wellbeing** - ATSI children with cancer and their families are better able to manage their emotional and mental health (e.g. feeling heard and understood - at least 75% of ATSI families feel this way).

Peer Support and Mentor Program

Establish facilitated peer support group and a new individual lived experience peer support mentor program to strengthen support further and empower the community of families going through childhood cancer.

Program cost: \$2.6m over six years

Deliverables:

- Establish facilitated groups and individual support program
- Establish lived experience mentor program
- By year 3: 800 families supported; by year 6: 2,000 family members supported

Outcomes:

- **Connection** - families have meaningful connections throughout their child's cancer experience (e.g connected to other families facing childhood cancer, feeling part of a community that understands, feeling less alone - at least 85% of people supported by specialist service to feel this way after a period of consistent support e.g. 6+ months)

Childhood cancer threatens the immediate and long-term mental health and wellbeing of the patient and all family members.

If left unaddressed, the consequences of poor mental health and wellbeing may be far-reaching and difficult to manage.

It is critical to urgently address unmet needs to support mental health and wellbeing, with over two-thirds of families affected by childhood cancer missing out on specialised emotional and mental health support. This requires an integrated, person-centred model in paediatric oncology with a focus on prevention and early intervention.

For further information or any additional queries relating to this Submission, please contact:



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