



# *outcomes report*

The difference Redkite is making for children and young people with cancer and their families

2015/16

Released 2017



## **contents**

Foreword	3
Redkite's five key outcome areas	4
<b>Outcome 1: Access to support</b>	<b>5</b>
Why is this important?	5
What are we doing?	5
Access to support: outcomes achieved 2015-16	6
<b>Outcome 2: Skills, knowledge and resources</b>	<b>8</b>
Why is this important?	8
What are we doing?	9
Skills, knowledge and resources: outcomes achieved 2015-16	9
<b>Outcome 3: Connection, support and understanding</b>	<b>11</b>
Why is this important?	11
What are we doing?	11
Connection, support and understanding: outcomes achieved 2015-16	12
<b>Outcome 4: Emotional wellbeing</b>	<b>14</b>
Why is this important?	14
What are we doing?	14
Emotional wellbeing: outcomes achieved 2015-16	15
<b>Outcome 5: Supported families and networks</b>	<b>17</b>
Why is this important?	17
What are we doing?	17
Supported families and networks: outcomes achieved 2015-16	18
Next steps	19
Bibliography	20

## foreword

This year, in Australia, it's estimated that 1650 children and young people (up to 24 years) will be diagnosed with cancer, <sup>1</sup> meaning a child or young person is diagnosed every six hours. A cancer diagnosis places significant demands and pressure on these children and young people, as well as their families, extended families, friends and other support networks. Treatment can be gruelling, often requiring long hospitalisation and many days in outpatient clinics, and it can last for years. For many families this may mean moving to metropolitan or regional hospitals for treatment, often requiring one parent to leave work to be with the diagnosed child. Families can find themselves dealing with a loss of income and increased expenses at the same time as they are coping with intense emotional and psychological stress. While the end of treatment may be a time to celebrate, survivors can face physical, neurocognitive and psychosocial late effects due to their cancer or treatment.

At Redkite, we provide essential support to children and young people (0-24 years) with cancer, their families, friends and support networks, to help them cope with financial, emotional, practical and education-based challenges. Our support includes:

- ◆ diagnosis support packs for children and young adults
- ◆ support in hospital through social workers and music therapists
- ◆ financial assistance to cover essential costs
- ◆ information, counselling and group support
- ◆ support to keep education and career goals on track
- ◆ support through grief and loss

We know that while it is important to report on what we do and how much of it we do, it is just as important to understand and measure the difference it makes to the people we support. Over the past few years we have been building our capacity to understand, measure and report on the outcomes of our services.

This report presents the outcomes we have been working towards and what we achieved in 2015 and 2016. It clearly outlines the strengths of Redkite's services in creating positive outcomes for the people we support, and in helping us fulfil our purpose of ensuring the best possible quality of life for children and young people with cancer and their families – now and into the future.

Nevertheless, there is still much to be done. Our work in outcomes measurement has helped us identify opportunities to increase the impact of our services and better meet the needs of children and young people with cancer and their families. We will continue to explore these opportunities in 2017 and beyond.

I would like to thank our partners and the community for their generosity in supporting Redkite, without which we would be unable to achieve these important outcomes for children and young people with cancer and their families.



**Jenni Seton**  
Chief Executive Officer, Redkite

## Redkite's five key outcome areas

Redkite has long recognised the importance of understanding and improving the outcomes of our services for children and young people with cancer and their families; and over the past few years, we have been building our capacity to measure and report on those outcomes. As part of this work, throughout 2014 and 2015, we developed an overarching client outcomes framework to clearly communicate the outcomes we hope to achieve for the people we support, and to guide the monitoring, evaluation and development of our services.

Our client outcomes framework is presented on the following page and forms the basis for this report. The framework identifies the five overarching outcome areas, and more specific outcomes, that Redkite prioritised in 2015 and 2016. Together, these outcomes contribute towards our overall purpose of creating the 'best possible quality of life for children and young people with cancer and their families'.

The outcomes were developed using findings from internal and external research and evaluations (including previous Redkite client consultations), existing Redkite program logic models, and the knowledge and experience of Redkite professionals.

This report describes the significance of each outcome area, how Redkite is working towards those outcomes, and the outcomes we achieved in 2015 and 2016. So far, our work in outcome measurement has focused on our community-based support services and therefore the 'outcomes achieved' sections of this report do not include data relating to the 18 hospital-based social work and music therapy positions funded by Redkite. We hope to be able to include these in future reports.

REDKITE'S PURPOSE IS TO ENSURE THE

## best possible quality of life for children and young people with cancer and their families

TO ACHIEVE THIS WE FOCUS ON FIVE OUTCOME AREAS:

- |                               |   |   |                                 |   |
|-------------------------------|---|---|---------------------------------|---|
| <b>1</b><br>ACCESS TO SUPPORT | <b>2</b><br>SKILLS, KNOWLEDGE AND RESOURCES | <b>3</b><br>CONNECTION, SUPPORT AND UNDERSTANDING | <b>4</b><br>EMOTIONAL WELLBEING | <b>5</b><br>SUPPORTED FAMILIES AND NETWORKS |
|-------------------------------|---|---|---------------------------------|---|

WE WANT THE PEOPLE WE WORK WITH TO BE ABLE TO SAY:

*I am aware of and can access quality support, whenever I need it, wherever I am*

*I have skills, knowledge and resources to help me through the cancer experience*

*I feel connected, supported and understood*

*My emotional wellbeing is the best it can be*

*Those who support me are informed, supported and better able to assist me*

WHICH MEANS:

- ◆ I know about support services relevant to me and my family
- ◆ I can access services I need at hospital, home and in the community
- ◆ I can access services at the time I need them
- ◆ I can access

- ◆ I am well informed throughout all stages of my cancer experience
- ◆ I feel equipped to manage my situation
- ◆ I have skills to help me manage the impact of cancer on my life
- ◆ I have access to a range of relevant resources to help me manage.

- ◆ There are people I can talk to who 'get it'
- ◆ I have a network of people who support me
- ◆ I feel confident in my connections to professionals and organisations

- ◆ I recognise the strengths I have
- ◆ I recognise that it's not unusual to feel the way I do in my situation
- ◆ I am able to maintain positive relationships with the people closest to me

- ◆ I know that my family and support networks are supported to manage their own cancer experience
- ◆ The people who support me are well equipped to do so



## access to support



*"I am aware of and can access quality support, whenever I need it, wherever I am".*

### Which means:

- ◆ I know about support services relevant to me and my family
- ◆ I can access services I need at hospital, home and in the community
- ◆ I can access services at the time I need them
- ◆ I can access services how I want to

### Why is this important?

Cancer in childhood, adolescence and young adulthood is a highly stressful experience that challenges and disrupts all aspects of life. It can put significant demands and pressures on the person diagnosed as well as their family, extended family, friends and their community. After diagnosis and during treatment, families often experience significant upheaval as they deal with a potentially life threatening diagnosis<sup>2</sup>, as well as

*"I would have liked to have been told about Redkite a lot sooner at my son's first diagnosis, it was an extremely difficult time for us... and I had no support and no one to talk to or help."*

Bereaved parent, 2016

the extra demands, stresses and responsibilities that come with it.<sup>3-5</sup> In addition, families often face extra expenses while experiencing a drop in or a loss of income<sup>6</sup>.

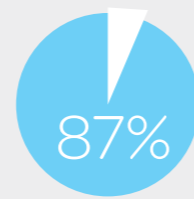
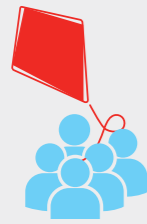
The impact of cancer doesn't end when treatment finishes. After completing treatment, cancer survivors are at risk of physical,<sup>7-11</sup> neurocognitive and psychosocial late effects and their parents may continue experiencing psychological stress for years to come<sup>12</sup>.

Access to quality social support can assist families to manage more effectively, helping alleviate some of the impacts of cancer<sup>12-13</sup>. Despite this need, families often don't get the right support at the time they need it. In a recent survey of Redkite's clients, 74% said they would have liked to have heard about Redkite at or even before diagnosis, yet only 48% of clients did – a difference of 26%; and many reported being unaware of services provided by Redkite that could have been of benefit to them<sup>17</sup>. Redkite believes families should be made aware of relevant support services (both those provided by Redkite and those provided by other organisations) as soon as they're able to benefit from them; and that they should be able to access those services where, when and how they need them.

### What are we doing?

- ◆ We provide support through all stages of the cancer experience, from diagnosis and treatment through to survivorship, palliative care, and bereavement. This includes funding social work and music therapy in hospitals, as well as delivering support directly to families in the community.
- ◆ We distribute support packs at the time of diagnosis, so families and young people know about Redkite and our support services.
- ◆ We provide high quality community-based support that is flexible in where, when and how it is delivered, for example, our social work and education and career services can be accessed in person, by phone or by email.
- ◆ We build awareness of Redkite and our services through partnerships, marketing and other communications.
- ◆ We are constantly exploring opportunities to develop new services and products in response to identified needs and gaps, while avoiding duplication of existing services.
- ◆ We direct families and professionals to relevant, existing services where these are high quality and could be of benefit.

# Access to support: outcomes achieved 2015-16



## Increased awareness of Redkite's services

Between January 2014 and December 2016, awareness of Redkite as a charity **increased from 47% to 54%** among the Australian population, meaning more people are aware of Redkite's services, even before they are diagnosed.

All families who provided feedback about receiving our paediatric Red Bag reported having better knowledge about Redkite's services as a result.<sup>15</sup>

## Increased number of people supported

Throughout 2015 and 2016, Redkite provided community-based support (including information, counselling, financial assistance and bereavement support) to over 5500 individuals. We also supported many more families through our funding of hospital-based social work and music therapy.

In 2015, we supported over 3300 individuals with community-based support, an increase of 7% from 2014; and in 2016 we supported just over 3700, an increase of 11% from 2015. This means more people are accessing Redkite's essential community-based support services.

## Access to Redkite's support, regardless of treatment stage

In 2016, **87% of Redkite's clients agreed** that Redkite is available to provide support **at all stages of the cancer journey**.<sup>14</sup>

## Timely access to support

**More than 9 out of 10 Redkite clients are satisfied with how quickly they receive support** from Redkite's Financial Assistance service, Community Based Social Workers, and/or Education and Career Support Consultants.<sup>17</sup>

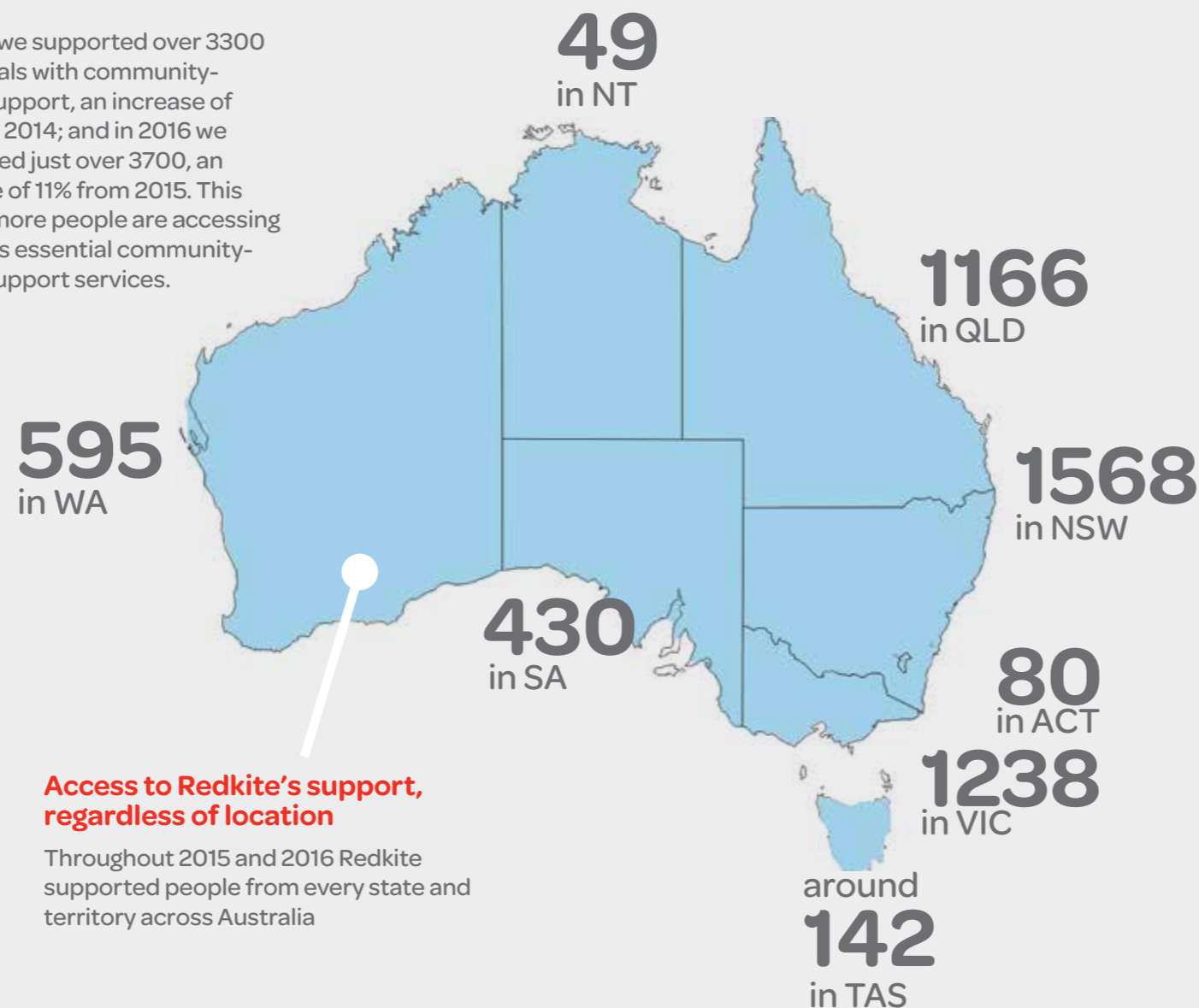
## New services and products to meet needs

Since the beginning of 2015, Redkite has introduced new products and services to close identified gaps in support for families, including:

- ◆ single-session information telegroups for specific audiences, such as dads, grandparents, and parents of a child with a brain tumour
- ◆ running a Family Wellbeing Program at the Children's Hospital, Westmead
- ◆ establishing 'Kite Connectors', a community of people affected by childhood or youth cancer who provide knowledge and advice to Redkite.
- ◆ two new resources for bereaved families – an information and support pack and 'By My Side', a book that shares the experiences of bereaved parents
- ◆ Face to face community-based counselling (previously only available by phone or email)

## Connection to other services

In 2016, the vast majority (**81%**) of Redkite's clients agreed that as result of the support they received from Redkite, they **know how to connect to ongoing support**.



## Access to Redkite's support, regardless of location

Throughout 2015 and 2016 Redkite supported people from every state and territory across Australia

**"Redkite's Education and Career Support Service is just a really great, great thing to be able to access for our young people because it really was a gap."**

– Health professional, 2015

## skills, knowledge and resources



*“I have skills, knowledge and resources to help me through the cancer experience.”*

### Why is this important?

- ◆ I am well informed throughout all stages of my cancer experience
- ◆ I feel equipped to manage my situation
- ◆ I have skills to help me manage the impact of cancer on my life
- ◆ I have access to a range of relevant resources to help me manage

### Why is this important?

Families are unlikely to have experienced anything like the diagnosis of a child or young person with cancer before, and they may need new skills, knowledge and resources to manage the challenges they face. Most families have a critical need for information,<sup>16</sup> including information on treatment, side effects, emotional support, practical matters and resources. Providing access to good quality information, and the support to use it, can increase families peace of mind and help them to feel some level of control over their

We provide counselling and group support delivered by qualified Social Workers to help families develop skills and strategies to manage their experience.

situation.<sup>17,18</sup> Families may also benefit from support to help them gain different coping skills, which can help to reduce emotional distress.<sup>19</sup> Families and young people may also need support with the financial and material impacts of a cancer diagnosis. Parents of a child with cancer often face extra expenses while experiencing a drop in or loss of income; and these additional financial difficulties can in turn result in increased emotional distress<sup>20</sup>. Providing financial support to families at this time can improve emotional wellbeing, reduce exposure to problem debt and help to retain a sense of normality.<sup>21</sup>

***“You want to be strong and be there for your child. That’s all you should have to focus on. But the bills don’t stop coming.”***

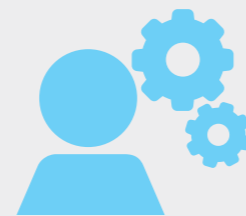
Parent of a child diagnosed with cancer, 2014<sup>21</sup>

Young people with a cancer diagnosis can experience uncertainty, alienation, loss of control, and resentment. Providing information in an age-appropriate manner can help prevent or alleviate these difficulties.<sup>22</sup> In addition, diagnosed young people often experience significant interruptions to their education and their career, and may experience issues with reintegration, peer relationships and long term educational attainment and employment.<sup>23</sup> Childhood cancer survivors are twice as likely as the general population to be unemployed; and survivors of brain tumors are five times as likely.<sup>24</sup>

### What are we doing?

- ◆ Our specialist Education and Career Support Consultants help young people (aged 15-24 years) to stay on track or re-engage with school, university or work, or to pursue new education and career goals.
- ◆ Our information and support line is available for young people, families and health professionals, 9am-7pm AEST.
- ◆ We provide financial assistance, helping young people and families to cover costs such as bills, groceries, petrol and rent or mortgage payments.
- ◆ We provide education grants to children, teenagers and young adults to pay for expenses like tutoring, equipment, materials and school fees.
- ◆ We provide information resources free of charge, including a free Redkite Book Club for all ages.
- ◆ We provide community counselling and group support delivered by qualified Social Workers to help families develop skills and strategies to manage their experience.
- ◆ We are continuing to develop and expand our information services, including digital information that can be accessed 24/7, because we know that families and young people still have unmet information needs.

## Skills, knowledge and resources: outcomes achieved 2015-16



### Increased knowledge

88%

of families who provided feedback about receiving our paediatric Red Bag felt better informed about the cancer experience as a result.<sup>15</sup>

84%

of people who used Redkite's information, support and counselling service and 76% of those who received books and resources from Redkite felt more informed as a result.<sup>14</sup>

In 2015, a survey of young people who had received education and career support from Redkite found:

83%

had increased knowledge of opportunities available to them

58%

had learned things that helped them get back into school, work or study.<sup>25</sup>

***“Our social worker was very helpful and ensured I was well informed about several issues that I was going through, and also provided me with the information I needed to help me get through it.”***

Parent, 2016<sup>14</sup>

### Increased skills, strategies and ideas

As a result of accessing Redkite's information, support and counselling service:

70%

of clients felt they had identified strategies to help manage their situation

66%

better understood their skills and strengths<sup>14</sup>

81%

of parents who took part in a 2016 parent group, led by Redkite Social Workers at a Camp Quality camp, left the group with new ideas that they felt would help them manage day to day.<sup>26</sup>

***“The little booklets that had pointers on how to cope with Christmas and other events was great to put protective barriers in place and get through some difficult situations”***

Parent, 2016<sup>14</sup>

### Feeling more equipped to manage

82%

of Redkite's clients felt more equipped to support their family and 70% felt more in control of their own or their child's care as a result of the support they received from Redkite overall.<sup>14</sup>

After accessing Redkite's financial assistance,

89%

of clients reported feeling more equipped to manage their situation.<sup>14</sup>

In 2015, among young people surveyed who had received education and career support from Redkite:

71%

felt more able to manage the impact that cancer may have on their work or education

54%

felt they could cope better when things were difficult with their work or education.<sup>25</sup>

### Participation in education and employment

In 2015, among young people surveyed who had received education and career support from Redkite:

75%

had since decided on the next steps for their future

38%

had returned to school or work or TAFE/college/uni

33%

had signed up for or taken a course, and

21%

had started work experience or volunteering.<sup>25</sup>

***“My Consultant opened my eyes to a new career. I found it really scary after finishing with treatment because I wasn't sure what to do with my life. My consultant asked me about my previous qualifications and together we worked out what career suited me.”***

Young person, 2015<sup>25</sup>



## connection, support and understanding



*“I feel connected, supported and understood.”*

### Which means:

- ◆ There are people I can talk to who ‘get it’
- ◆ I have a network of people who support me
- ◆ I feel confident in my connections to professionals and organisations

### Why is this important?

Cancer can be an isolating experience; it impacts on all aspects of life and can significantly disrupt connections with family, friends, classmates and colleagues, just when those support networks are needed the most. Families may relocate for part or all of a child or young person’s treatment,<sup>20</sup> meaning that they are less able to rely on any local support networks. In addition, many children and young people with cancer experience significant absence from school or work, interrupting connections and relationships with their peers.<sup>27</sup>

A lack of psychosocial support during this time can impact negatively on wellbeing and quality of life. Access to ongoing support, including peer support and support from professionals, is critical to help families and young people cope with the challenges they face.<sup>13,28,29</sup>

Redkite’s Social Workers offer individual support that can help parents or young people communicate with their treating team.

Families and young people have told us that they want to speak to people who ‘get it’, including other families or young people who are going through a similar experience,<sup>30</sup> as well as professionals who understand and specialise in cancer support.<sup>14</sup> Being listened to and hearing from others going through similar experiences can help to reduce the sense of isolation that families often feel.<sup>31</sup>

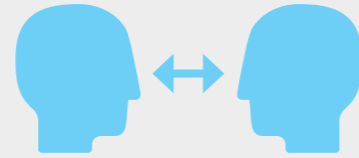
*“It was really isolating, total isolation. In amongst the busyness we were isolated as a family, all of us there, brothers and sisters, my husband and myself. We were all supported by our family and friends, but within that we were isolated as we weren’t in with other cancer people.”*

Parent of a child with cancer, 2014<sup>30</sup>

### What are we doing?

- ◆ Redkite professionals understand the hospital and treatment environment and the context that families and young people have been part of. They work with people’s strengths, providing extra support to help individuals to stay resilient through the challenges that cancer can present.
- ◆ Our phone-based support ‘telegroups’ enable people to connect with others in similar situations from the privacy of their own home (or from the hospital). Groups are tailored to people’s specific situations, needs and circumstances and include special groups for bereaved parents.
- ◆ Redkite Social Workers provide professionally supported peer groups for parents attending Camp Quality Family Camps.
- ◆ Our Education and Career Support Consultants run small workshops for groups of young people to meet and work on resumes, LinkedIn pages or other skills.
- ◆ Redkite’s Social Workers offer individual support that can help parents or young people communicate with their treating team.
- ◆ Redkite is piloting approaches to work with hospital-based social workers to minimise gaps in support for young people and families at transition times for example. These include the move from intensive treatment to maintenance therapy; the transfer from hospital to home; the end of treatment; or following bereavement.
- ◆ We continue to explore opportunities to further assist families to connect and interact with one another, including through ongoing development of our group programs and exploring digital opportunities in this area.

# Connection, support and understanding: outcomes achieved 2015-16



## Feeling listened to

87%

of people who accessed Redkite's information, support and counselling service said they felt listened to as a result <sup>14</sup>

95%

of parents who took part in a 2016 parent group, led by Redkite Social Workers at a Camp Quality camp, said they felt 'heard' in the group <sup>26</sup>

***"Someone listening to my concerns and feelings and offering support... helped me when I was at my lowest point."***

Parent, 2016<sup>14</sup>

## Feeling understood

All families who provided feedback about receiving our paediatric Red Bag said they felt Redkite understands and is there to support them. <sup>15</sup>

96%

of Redkite's clients agreed or strongly agreed that it is important to them that Redkite specialises in cancer support. <sup>14</sup>

***"Your support and counselling services has provided me with the skills I need to help me get through my grief. It's comforting to know that your counsellors understand and never judge the thoughts of a bereaved mother. A shoulder to cry on once in a while is nice too."***

Bereaved parent, 2016<sup>14</sup>

## Feeling supported and less alone

80%

of people who accessed Redkite's information, support and counselling service and

69%

of people who received Redkite books or resources said they felt less alone as a result of that support. <sup>14</sup>

95%

of parents who took part in a 2016 parent group, led by Redkite Social Workers at a Camp Quality camp, said they left the group feeling less alone in their cancer experience. <sup>26</sup>

In 2015, of young people surveyed who had received education and career support from Redkite,

88%

said they know Redkite is there for them if they need support with work or education. <sup>25</sup>

***"It made me feel that I am not alone, that I have special people who understand my situation and are highly experienced to help me."***

Parent<sup>14</sup>

## Connections with other families or young people

Between 2015 and 2016, more than 300 young people, parents, grandparents and other family members connected with people going through similar experiences as part of a Redkite-facilitated group, information session or workshop.

***"Knowing there are people I can contact if I need advice or guidance has been very helpful and relieves anxiety related to my education and career."***

Young person with cancer, 2015<sup>25</sup>

## emotional wellbeing



*“My emotional wellbeing is the best it can be.”*

### Which means:

- ◆ I recognise the strengths I have
- ◆ I recognise that it’s not unusual to feel the way I do in my situation
- ◆ I am able to maintain positive relationships with the people closest to me

### Why is this important?

Cancer can have a considerable impact on the emotional wellbeing of a young person facing cancer, family members, or close supporters of the family. Young people diagnosed with cancer and parents of a diagnosed child or young person are at risk of anxiety, stress and distress throughout their cancer experience, sometimes months or years after treatment ends.<sup>32,33</sup> If the child or young person dies, the grief that follows lasts a lifetime.

At the end of a child or young person’s cancer treatment, it is common for young people and parents to experience feelings of uncertainty, including fears around relapse or death.<sup>2,12</sup> In a recent Australian study, 48% of young people diagnosed with cancer and 42% of parent caregivers scored above a clinical cutoff score for post-traumatic stress symptoms. In addition, 31% of young people and 28% of parent caregivers reported moderate to severely elevated symptoms of anxiety and depression.<sup>33</sup> Adding to the distress

experienced as a result of a childhood or adolescent cancer diagnosis is the unmet need for healthcare services. Recent Australian research suggests that where adolescents and parents have a high level of unmet needs, greater emotional distress also exists.<sup>34</sup>

However, families can have both positive and negative experiences during cancer diagnosis, treatment and in the following years. Everyone will bring their own strengths to the situation, but extra support can help people to stay resilient through the challenges ahead and work through the adjustment to the cancer diagnosis and any related family and relationship pressures. Learning to deal with the non medical aspects of cancer, including the aftermath of treatment, may help families and young people with a cancer diagnosis to engage with the positive side of their experiences.<sup>34</sup>

*“When you come home...everything stops. It’s almost like you’re in the middle of this incredible support structure and then it disappears, and it’s almost like “Oh, what’s next?” Talk about terrifying, I mean you’re at home with a still clinically-ill child...and it’s like you’re in no-man’s land; I mean that’s what we felt.”*

Parent of a child with cancer, 2014<sup>30</sup>

### What are we doing?

Redkite’s Social Workers offer individual face to face and telephone counselling to help people adjust to a cancer diagnosis, manage family and relationship pressures, deal with strong emotions, or share feelings and experiences in a safe, respectful space.

- ◆ Redkite’s Social Workers offer individual face to face and telephone counselling to help people adjust to a cancer diagnosis, manage family and relationship pressures, deal with strong emotions, or share feelings and experiences in a safe, respectful space.
- ◆ Redkite provides information and resources to families and young people that can help them to manage their situation and recognise that it is not unusual to feel the way they do.
- ◆ Redkite Social Workers and Education and Career Support Consultants help young people to explore and maximise their opportunities after treatment, and work with them to build confidence and self-esteem to make decisions about their future plans.
- ◆ By providing families and young people with financial assistance, Redkite helps to alleviate financial stress and pressure on families, allows them to spend more quality time together and support one another, and helps them to maintain a sense of normality.
- ◆ Redkite is working with key stakeholders in the paediatric oncology sector to develop a national framework for paediatric psychosocial support that aims to improve the quality and equity of psychosocial services delivered to children with cancer and their families in hospitals and the community across Australia.
- ◆ Redkite also provided funding to enable the delivery of a report into the psychosocial needs of adolescents and young adults who’ve experienced cancer. Led by Professor Susan Sawyer, Director of the Centre for Adolescent Health at RCH Melbourne, this project enables the completion and publication of an important piece of national research into youth friendly cancer support models and practice.

# Emotional wellbeing: outcomes achieved 2015-16



## Recognition of strengths

In 2015, of young people surveyed who had received education and career support from Redkite:

**71%**  
felt more optimistic about the future.<sup>25</sup>

Of the parents who took part in a 2016 parent group, led by Redkite Social Workers at a Camp Quality camp:

**79%**  
left the group feeling stronger

**75%**  
felt more optimistic after participating.<sup>26</sup>

***"It was helping me rebuild an image of myself and figuring out who I am after the chemo, because I'm not who I was before the chemo, and I'm not who I was during the chemo, I'm someone completely different now who I feel proud about."***

Young person receiving education and career support from Redkite, 2015<sup>25</sup>

***"I've had more confidence and I have found my goals more believable."***

Young person receiving education and career support from Redkite, 2015<sup>25</sup>

## Recognising feelings are not unusual

**82%**  
of people who accessed Redkite's information, support and counselling service and

**72%**  
of people who received Redkite books or resources said they recognised that it is not unusual to feel the way they do as a result of that support.<sup>14</sup>

## Positive relationships

Of people who accessed Redkite's financial assistance:

**82%** felt pressure on their family relationships was reduced

**76%** felt better able to maintain a sense of normality

**72%** felt better able to stay connected with people close to them.<sup>14</sup>

**74%** of people who accessed Redkite's information, support and counselling service said they pressure on family relationships was reduced as a result.<sup>14</sup>

***"The Financial Assistance... eased the pressure I was undergoing [so I] could concentrate more on my son's care without more stress."***

Parent, 2016<sup>14</sup>

***"The fuel and food vouchers allowed us to maintain a sense of normalcy around Christmas."***

Parent of a child with cancer, 2016<sup>14</sup>

## supported families and networks



*“Those who support me are informed, supported and better able to assist me.”*

### Which means:

- ◆ I know that my family and support networks are supported to manage their own cancer experience
- ◆ The people who support me are well equipped to do so

### Why is this important?

Redkite believes that for a child or young person diagnosed with cancer to have the best possible quality of life, the people who support them – their family, friends, partners, health and education professionals – need to be well supported themselves. We know that a family’s strengths can provide a protective mechanism for young people with cancer.<sup>33</sup> Despite this, recent Australian research found that parent carers often have unmet needs for health care services during and even following treatment, with 38% of parents having two or more unmet needs after treatment.<sup>34</sup> At the same time, children and young people are often keenly aware of the impact of their diagnosis on those around them and want to know that their

family members are themselves being supported. For example, young people may recognise the additional financial burden their treatment places on their family and wish for support to be available to ease that burden.<sup>13</sup>

Different family members often step in to provide support and take on practical or caring responsibilities to relieve the burden on parents, however, their ability to provide that assistance can be impacted by their own unmet needs. Grandparents often play a vital role in supporting family members, yet often keep quiet about their own distress, while looking after everyone else’s needs. This can affect their own wellbeing and their ability to support the family.<sup>35</sup> Support that is specifically designed for grandparents can help them, as well as their families. Similarly, siblings experience significant changes in family relationships and dynamics and may take on additional chores and responsibilities to reduce the burden on their parents.<sup>36</sup> Yet siblings can experience their own loneliness, isolation or sadness and have their own needs unmet.<sup>36,37</sup> Communication, information and support can help siblings increase their understanding of their sibling’s illness and their own potential involvement in the care of the diagnosed child or young person.<sup>36</sup>

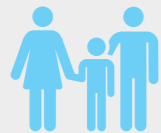
As well as the demand on family and friends, there is increasing demand on hospital based services to meet information and support needs; and there will always be limits and constraints on what they are able to provide. Assistance to help professionals support their clients can help to alleviate some of that demand.

### What are we doing?

- ◆ Redkite offers support not only to the immediate family of a child or young person facing cancer but also to their extended family and support networks, helping them manage their own experiences and also support the diagnosed young person. This includes support for grandparents (including telegroups and resources specifically for grandparents) and support for siblings (including sibling-specific resources).
- ◆ Redkite supports professionals (including health, allied health, community and education professionals) by providing referral pathways and information, advice, and resources that they can use to support their clients (e.g. hard copy and web based information; hard copy books and leaflets; and Red Bags and support packs).
- ◆ Redkite produces a monthly newsletter, the ‘Redkite Report’, specifically to update professionals on the different ways Redkite can support their work.
- ◆ Redkite is also currently developing an online information hub for families and supporters facing childhood or adolescent cancer, as well as young people themselves, to help make it easier to find quality, practical information about cancer online.

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## Supported families and networks: outcomes achieved 2015-16



### Assurance that families are supported

83%

of people who accessed Redkite's information, support and counselling service felt that there was support for their families and networks if they wanted it.<sup>14</sup>

***"The information helped inform my family how I felt and (what) choices I made... the support was great."***

Young woman with cancer, 2016<sup>14</sup>

### Equipped support networks

Of professionals who had been in contact with Redkite over the previous year:

98%

believe that Redkite helps them to support their clients, and

91%

felt informed about Redkite services that can help them support their clients.<sup>14</sup>

Of young people and family members who had been in contact with Redkite over the previous year:

82%

of clients felt more equipped to support their family

71%

felt more in control of their/ their child's care.<sup>14</sup>

***"I could not do my job or deliver the quality of service to adolescents and young adults without the support of Redkite services."***

Cancer Nurse Coordinator, 2015<sup>14</sup>

## next steps

Measuring the outcomes of Redkite's work for children and young people with cancer and their families has provided significant insight into the difference our services make, as well as a deeper understanding about the needs of the people we support.

It is clear that Redkite services create positive outcomes that contribute to our overall purpose of ensuring the best possible quality of life for children and young people with cancer and their families.

As referenced throughout this report, we will continue to look for opportunities to better help us to deliver these outcomes. For example:

- ◆ We are collaborating with key organisations and individuals across the paediatric oncology sector to develop a national framework for paediatric psychosocial support. Our goal is to develop and implement a framework that improves the quality and equity of psychosocial services delivered to children with cancer and their families in hospitals and the community across Australia.
- ◆ We know that the information needs of families and young people will continue to grow, so we will continue to develop and expand our information services, including digital information that can be accessed 24/7.
- ◆ We are piloting approaches to work with hospital-based social workers to increase referrals to our community-based support, and therefore minimise gaps in support, at key transition times; for instance, when treatment ends.
- ◆ We continue to explore opportunities to further assist families to connect and interact with one another, including through development of our group programs and exploring digital opportunities in this area.

Redkite is an organisation that is committed to learning and improving, so we will continue to develop and refine our approach to measuring the outcomes of our services. We will regularly ask our clients about the outcomes they have experienced and the outcomes that matter most to them. The results in this report are now our baseline. Importantly we will now strive to improve these outcomes over time, knowing that the difference the outcomes make to the people we support can contribute to the best possible quality of life for children and young people with cancer and their families.

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