

# Snapshot: Redkite Family Wellbeing Program Evaluation

## background

Redkite has been offering support to families at The Children's Hospital at Westmead (CHW) through the Family Wellbeing Program (FWP) since mid-2015.

The purpose of the FWP is to improve the wellbeing of oncology families during their hospital stay by providing practical and emotional support, activities and parental self-care services. It does this through providing the following services:

- ◆ The provision of a Family Support Coordinator (FSC) on the oncology ward at CHW to provide oncology families with information and practical and emotional support. The FSC is funded to provide services four days per week, with some of this service part funded by Cure Our Kids New Caledonia

- ◆ Distribution of the Redkite diagnosis packs to newly diagnosed patients
- ◆ *The Bead Program* where children are given a bead by the FSC to add to their personalised bead string which marks each cancer milestone as they progress through their treatment
- ◆ Groceries delivered on a weekly basis to the Family Room in CHW's oncology ward for use by oncology families
- ◆ Activities on the oncology ward and in the clinic – weekly afternoon tea sessions, beading, craft activities and face painting – supported by the FSC and Redkite volunteers
- ◆ Hairdresser and pamper sessions for oncology families delivered by qualified volunteers

- ◆ The provision of a CHW-specific oncology diary for families to help manage treatment protocols and appointments

***“The shock of hearing that your child is sick, particularly when the ‘cancer’ word is used, it was devastating ... once the shock subsides then you start to think of the logistics ... And then this lovely lady turns up with a bag and says this is for you from Redkite and here’s a parking voucher and a meal. The parent kitchen has food and is restocked every week. There’s a beading program, this week we have a hairdresser... it really makes a difference.”***

(Parent)

## program evaluation

We commenced an evaluation of this program in 2016 to better understand the difference it's making to oncology families at CHW and inform how we continue to deliver these services in the future. The evaluation sought to understand the following:

- ◆ How families, health professionals and others experience services offered by the program
- ◆ What aspects of the program are valued the most and why
- ◆ The value of the different elements in the program
- ◆ The efficiency of the program, in terms of how well it utilises Redkite's resources and maximises the impact for families

The evaluation was made up of two phases:

### Phase 1

(conducted in late 2016)



- ◆ A review of program participation data
- ◆ A series of in-depth interviews with 10 families who have participated in the program
- ◆ Eight in-depth interviews with Redkite staff and stakeholders closely associated with the

### Phase 2

(conducted in late 2017)



- ◆ Consultations with staff at CHW
- ◆ A quantitative survey with a larger sample of families involved with the program. In this online survey, a total of 76 respondents participated, yielding a response rate of 36%. Respondents included 65 parents/carers whose child has/had cancer, nine bereaved parents, and two young people who had been diagnosed with cancer.

## key findings

### Participation and usage



99%

of families received a Redkite diagnosis packs



91%

of families participated in the Bead Program



79%

of families used the groceries provided in the Family Room



64%

of families attended an activity on the ward



54%

of families used the hairdresser and pamper sessions

*"I had no clothes, I had nothing and that's why (the FSC) was just my shining light because she turned up with that amazing (red) bag. She was my first contact with a charity...and she turned up with that amazing bag which had all the toiletries and the keep warm cups and just everything in there ... it just meant so much, it was like a big bag of love."*

(Parent)

### Outcomes for families

#### Access to support:

90% of families agreed the FWP was an opportunity to be informed about Redkite early on

83% felt better informed about the services and support available to them

#### Increased skills, knowledge and resources:

85% of families agreed that the Program helped give them the skills, knowledge or resources to better manage their situation

#### Improved emotional wellbeing:

76% of participants agreed the Program provided the opportunity to talk to people who understood their situation

#### Distraction:

79% of families agreed that the Program provided an opportunity to do some type of productive, useful activity

#### Improved parental self-care:

72% of families agreed that the Program helped to improve their physical wellbeing

### Satisfaction with the program

91%

of families who took part in the Program were very satisfied or satisfied with the quality of the packaged groceries in the Family Room of the oncology ward

89%

were satisfied with the quality of their interaction with the FSC

87%

of families were very satisfied or satisfied that they could access the FSC when they needed to

## conclusions

The Family Wellbeing Program is currently delivering a variety of positive outcomes for oncology families at The Children's Hospital, Westmead. There is evidence of the Program contributing to both more practical outcomes (e.g. improved access to practical support) as well as more emotionally-based outcomes (e.g. enhancing emotional wellbeing; feeling connected, supported and understood).

The provision of groceries in the Family Room of the Camperdown ward are widely and frequently utilised. Parents value this service as it eases the financial burden of being in hospital, and provides practical support by attending to their physical wellbeing.

The Family Wellbeing Program helps create stimulation for families in the oncology ward, particularly through the afternoon teas and crafting activities run by the Family Support Coordinator. The Bead Program is another contributor to these positive outcomes and was strongly endorsed by families. Many of the positive outcomes for family members involved in the Program are a result of engaging with the Family Support Coordinator based at The Children's Hospital, Westmead.

While the hairdressing and pampering services do distract parents and can positively contribute to the emotional wellbeing of families, according to parents the value of them was perhaps not as high as other components of the Program.

***"The Bead Program is a tangible way to record your child's progression through treatment. It tells his/her story. It is a reminder of all he, and we as a family, have been through. The kids like the beads despite their inference; they are colourful, the kids can be involved in the making up of the chain, and they help us all remember how far we have come."***

(Parent)

The Family Wellbeing Program, with the support of The Children's Hospital Westmead staff, offers services and activities that are highly relevant to the current needs of parents and patients that were previously unable to be met by the hospital.

***"It made a massive difference, we didn't feel isolated as a family, we got to know people around the hospital and we actually had the ability to relax and stuff - it was a big winner."***

(Parent)



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## more information

For more information about this project, please contact the Redkite Research, Evaluation and Innovation team by calling **1800 733 548** or emailing [re@redkite.org.au](mailto:re@redkite.org.au)

Redkite is a national charity providing essential support to children and young people with cancer (0-24 years) and their families and support networks.

**1800 REDKITE (1800 733 548)**

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