

voices of oncology families and their support networks – a Redkite national survey



background

Redkite offers support to children and young people (24 years and under) with cancer, their families and professionals supporting those families. Support is available from diagnosis, throughout treatment, and after treatment ends and includes:

- ◆ financial assistance to cover essential costs
- ◆ education and career support
- ◆ community-based information, support and counselling
- ◆ books and resources
- ◆ funding for in-hospital social workers and music therapists.

objectives

The objectives of this study were to:

1. measure satisfaction with Redkite
2. measure perceived outcomes for families
3. measure perceived quality of Redkite's services
4. explore the ways in which Redkite services are being used
5. identify opportunities for service improvements

method

Tailored surveys were delivered to each of the following groups:

1. Support professionals - 85 health, community and education professionals who had been in contact with Redkite over the previous 12 months took part in the survey (a response rate of 33%). Of these, 60% were social workers, while the remainder were a mix of other types of professionals. Participants were spread across a range of work places and sectors.
2. Young people with cancer and their families ('families') - 240 respondents participated in the survey (a response rate of 22%). Respondents included 31 young people who had been diagnosed with cancer and 209 members of the support networks of a child/young person who has/had cancer. The support networks included parent/carers, grandparents and siblings.

key findings

satisfaction with Redkite and its services

There was high satisfaction with Redkite overall for both professionals and families:

- ◆ 97% of both professionals and families were **satisfied or very satisfied** with Redkite overall.

- ◆ 95% of professionals and 88% of families agreed that Redkite had **exceeded or met their expectations** in the past 12 months

- ◆ 99% of professionals and 98% of families would **recommend Redkite** to other professionals/someone else in a similar situation.

“From the person who answers the phone to the services and resources in the community, Redkite represents competent, friendly and accessible services”

- Social Worker

outcomes for families

Redkite believes that for a child or young person 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.

The professionals survey findings indicate that Redkite is playing an important part in supporting and equipping professionals to provide support to families:

- ◆ 98% of professionals strongly agreed or agreed that Redkite **helps them to support their clients**.

“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

Redkite is also helping clients to support their own families and know where to go to connect to ongoing support:

- ◆ 82% of families agreed or strongly agreed that they **felt more equipped to support their family**

- ◆ 71% of families felt **more in control** of their/their child’s care

- ◆ 83% of families know how to **connect to ongoing support**

Outcomes specific to individual services are presented in the table on page 4.

quality of Redkite services

The survey asked professionals and families about a number of service quality areas: ease of access, service staff, relevance and usefulness (of resources), responsiveness and equity. Overall, there was high satisfaction with each of these areas. The findings demonstrate that both professionals and clients who use Redkite’s services perceive them to be of a high quality.

- ◆ 99% of professionals and 92% of families agreed or strongly agreed **Redkite staff are professional**

- ◆ 95% of professionals and 91% of families agreed or strongly agreed **Redkite responded appropriately to their clients’/ their needs**

- ◆ 86% of professionals and families agreed or strongly agreed **services were appropriate for their clients’/ their cultural needs or background**

“The staff were so friendly, understanding and informative as well as caring.”

- Parent

In addition the survey found:

- ◆ 96% of families said it is important to them that Redkite **specialised in cancer support**

- ◆ 97% of professionals and 96% of families agreed or strongly agreed they **trust and value Redkite**

- ◆ 95% of professionals and 94% of families agreed or strongly agreed Redkite treats clients/me with **compassion and respect**

- ◆ 95% of professionals agreed or strongly agreed Redkite **delivers what is says it will**

- ◆ 95% of professionals agreed or strongly agreed Redkite is **collaborative**

- ◆ 94% of professionals agreed or strongly agreed Redkite **complements other services** available

- ◆ 87% of families agreed or strongly agreed Redkite is **available for support at all stages** of the cancer journey

Perceptions of the quality of individual services are presented in the table on the following page.

service use

Financial Assistance had the highest referral rate among professionals surveyed, with 92% of respondents having referred clients to the service; this was followed by Information, Support and Counselling (73% had referred) and Education and Career Support (54%).

more information

For more information about this review, please contact the Redkite Research, Evaluation and Innovation team by calling 1800 733 548 or emailing 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) | www.redkite.org.au

In line with this, Financial Assistance was also the most utilised service among families, with 85% of respondents having received Financial Assistance, followed by Information, Support and Counselling (57%), Books and Resources (45%) and Education and Career Support (32% of young people).

Where professionals had referred clients to Redkite's services, the majority had done so repeatedly, indicating that they were sufficiently satisfied with the quality and outcomes of the service to refer again.

“Redkite took the pressure off by helping pay for groceries when I gave up work for a time to care for my son.”

- Parent

conclusion

The results of these surveys were overwhelmingly positive, indicating that both professionals and families are satisfied with Redkite's services and that those services are perceived to be of high quality, contributing to positive outcomes for children and young people with cancer and their families.

The findings provide an important benchmark that can be used to measure changes in families' and professionals' perceptions of Redkite over time.

Although the findings were resoundingly positive, the detailed comments provided by participants are being used to identify and explore opportunities to continue to improve our services to better meet the needs of families and professionals.

“[What was helpful was] someone listening to my concerns and feelings and offering support. It helped me when I was at my lowest point.”

-Parent

Financial Assistance

Ease of access

Nearly all families were very satisfied or satisfied with:

- ◆ speed of receiving vouchers or bill payment (95%)
- ◆ being able to access the service as soon as needed (96%)

Education and Career Support

Ease of access

10/10* young people were very satisfied or satisfied with:

- ◆ contact methods
- ◆ speed of response
- ◆ hours of access

Service staff

- ◆ 10/10 young people very satisfied or satisfied with the quality of interaction with the ECS Consultants

Information, Support and Counselling

Ease of access

Most families were very satisfied or satisfied with:

- ◆ being able to access the service as soon as needed (93%)
- ◆ contact methods (90%)
- ◆ speed of response (90%)
- ◆ hours of access (82%)

Service staff

- ◆ 91% of families very satisfied or satisfied with the quality of interaction with Redkite's social workers

Books and Resources

Ease of access

Around three-quarters of families were very satisfied or satisfied with:

- ◆ speed of receiving resources (75%)
- ◆ ability to access resources when needed (72%)

After receiving Financial Assistance:

- ◆ 89% felt more equipped to manage their situation
 - ◆ 72% felt better able to stay connected with the people close to them
 - ◆ 82% felt pressure on their family relationships was reduced
 - ◆ 76% felt better able to maintain a sense of normality
- Skills, knowledge, resources
- Connected, supported, understood
- Emotional wellbeing

After receiving Education and Career Support:

- ◆ 10/10 felt better informed about opportunities available
 - ◆ 10/10 better understood their skills or strengths
 - ◆ 10/10 were clearer about the next steps in relation to education/ career
 - ◆ 10/10 were better able to manage the impact cancer had on their education/ career
- Skills, knowledge, resources

After receiving Information, Support and Counselling:

- ◆ 84% felt better informed
 - ◆ 70% identified strategies to help manage
 - ◆ 66% better understood their skills and strengths
 - ◆ 67% were better able to maintain connections
 - ◆ 87% felt listened to
 - ◆ 80% felt less alone
 - ◆ 82% recognised it is not unusual to feel the way they do
 - ◆ 74% felt pressure on family relationships was reduced
 - ◆ 83% felt there was support for their family/network
- Skills, knowledge, resources
- Connected, supported, understood
- Emotional wellbeing
- Supported families and networks

After receiving Books and Resources:

- ◆ 76% felt better informed
 - ◆ 66% identified strategies to help manage
 - ◆ 69% felt less alone
 - ◆ 72% recognised it is not unusual to feel the way they do
- Skills, knowledge, resources
- Emotional wellbeing

* Only 10 of the young people who answered the survey had received Education and Career Support. Their findings are presented out of 10 so