



# Child Cancer Foundation Social Impact Report 2023

The impact of Child Cancer Foundation on the overall wellbeing of families on their paediatric cancer journey

October 2023

Prepared by



HUBER  
SOCIAL



# Tō tuāoma timatatanga Ō kawenga pikau mahi Ka hāere tonu ia ra, ia ra Mō ō ratou oranga.

Your journey began  
With challenges day after day  
With integrity and commitment  
We support you and your whānau with empathy

.....

Huber Social acknowledges the traditional owners and custodians of country throughout Australia and acknowledges their continuing connection to land, waters and community. We pay our respects to the people, cultures and elders past, present and future.

Huber Social further acknowledges and respects ngā iwi Māori as the Tangata Whenua of Aotearoa and is committed to upholding the principles of the Treaty of Waitangi, fostering Huber's relationship with Māori and supporting Māori people.

Huber Social recognises First Nations peoples' knowledge, language and concepts from Australia and Aotearoa, which underpin our understanding of wellbeing and how it is measured.

This report was prepared and written on the lands of the Gadigal, Bidjegal, and Cammeraygal people of the Eora Nation.

Data was collected across Aotearoa New Zealand.



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# Walking alongside tamariki and their whānau on their cancer journey

Finding out your child has cancer turns your life upside down. Unfortunately this news is delivered to more than three families in Aotearoa New Zealand every week, none of whom ever expected this would happen to their child.

The difficult journey with child cancer is different for every family, and the nature of both the challenges they face and the support they need is unique to each. While medical staff do an incredible job treating the child, whānau and families often need emotional and practical support beyond what doctors and nurses are able to give. This could include support navigating of the medical system, maintaining healthy relationships, managing emotions, paying the bills, communicating their experience, or finding a community that can offer the support they need.

For over 45 years, Child Cancer Foundation (CCF) has stood by their kaupapa of ensuring that every family going through childhood cancer in New Zealand has someone there to support them at a time when they need it most, helping them overcome challenges and maintain control of their lives. They focus on the whānau, not the cancer, and support every family so they can concentrate on the most important thing of all, loving and caring for their child.

Child Cancer Foundation's 2022-2025 strategic plan includes four overarching pillars which provide direction for their mahi over this time. These are:

- Excellence in Our Practice
- Powerful Partnerships
- Knowledge Creation and Knowledge Transfer
- Developing our Assets



**Our goal is for each family to have the strength to say goodbye to us one day.**

To strengthen the empirical evidence of its impact and support the delivery of their mahi CCF has partnered with Huber Social to establish a measurement system that can both measure, and maximise, their social impact.

Results of this year's 2022-2023 measurement have built on the previous findings from 2020 and 2021, with tools being refined at each stage. It is important place the previous measurements in the COVID-19 pandemic context where many CCF services were impacted by the restrictions placed on domestic travel, hospital access, and social distancing measures.

Huber Social aims to support CCF to achieve their vision by offering a resource that can inform internal decision making, strengthen support from donors, and identify opportunities to collaborate with others, as well as satisfy accounting standards requirements.



# Why Measure Social Impact?

This is Child Cancer Foundation's third Annual Social Impact Report.\* CCF partners with Huber Social to measure its social impact, to both have evidence of its overall impact on families and to identify opportunities to maximise effectiveness and better allocate resources.

## 1. Measure

To measure the impact of CCF, Huber Social measures the shift in overall wellbeing and key outcomes for families across various stages of their cancer journey.

Measurement will provide a data driven approach for CCF to understand and articulate their social impact to internal and external stakeholders.

## 2. Maximise

Beyond a focus on target outcomes, Huber Social's approach considers the holistic needs of a person, in this case parents, family and whānau, to be in the best position to fulfil their potential.

This approach identifies opportunities to refine CCF services (if required) and best utilise resources to maximise the organisation's impact on wellbeing.

# Why Wellbeing?

*Measures overall progress and supports the systematic solving of social issues*

Ultimately, the goal of all social impact is to put people in the best position to fulfil their potential and achieve wellbeing. It is therefore important to measure wellbeing to ensure that overall, programmes are having a positive impact. To measure social impact, Huber Social therefore measures a shift in overall wellbeing and the specific programme outcomes that contribute to it.^

Taking a wellbeing approach also provides a whole-of-life understanding of a person's needs. Instead of starting with the issue at hand, which tends to focus on the crisis end of a problem and place artificial limitations on the needs of people, strengthening wellbeing supports building a person's capability and opportunity to fulfil their potential, thus working to systematically address social issues.



^2020 and 2021-22 annual reports.

\*For details of how Huber Social measures wellbeing, please refer to Appendix 1, the Huber Social Wellbeing Measurement Framework



#### CHILD CANCER FOUNDATION'S VISION

To walk alongside and support all children and their families on their cancer journey and work on advancing improvements to child cancer care.

*Kā haere tahi tatou tē taha ā tamariki, mē tē whānau katoa. I tēnei hikoī mate pukupuku hei rangatu ngā whanake hēi awhi ngā tamariki i tēnei mate pukupuku.*



# About Child Cancer Foundation

Child Cancer Foundation supports children with cancer and the people who love them. They walk alongside them every step of the way, helping them overcome challenges and maintain control of their lives.

Outside of medical treatment, CCF recognises the best way to support children with cancer is to provide wrap around support services to them and their families, with a focus on the parents as their primary carers. They offer and coordinate individualised support across Aotearoa New Zealand, with a team of Family Support Coordinators (FSCs) across the country. FSCs are the link between home and hospital; they are someone these families can turn to and be heard by, providing consistent care and empathy. Families can be connected into CCF-provided services and support including and by no means limited to: financial support, accommodation, wellness services, and memory-making opportunities.

Since July 2022, CCF has been guided by its new strategic plan for 2022-25 which represents its clear values and direction as an organisation.

**This renewed vision is anchored by four overarching pillars and themes:**

## Theme 1: Excellence in Our Practice

With the goal of walking alongside and supporting children and their families on their cancer journeys, CCF aims to demonstrate exemplary childhood cancer care through engagement with families and children; supporting mental wellness; and providing bereavement support.

To do this, FSCs support the whole family by helping them to normalise feelings, focus on a strengths-based approach, offer hope and comfort, and support caregivers own self-care. They coordinate family's engagement with CCF and provide information and access to other services like counselling and bereavement support.

Depending on the need of the specific family, financial and practical support may come in many forms including, as examples: food and meals, flights and accommodation, phone top ups, a holiday, or a full tank of petrol. CCF also provides access to Family Places, safe and clean physical spaces away from the hospital equipped to meet all family needs.

## Theme 2: Powerful Partnerships

CCF supports ground-breaking childhood cancer research to improve childhood cancer care. Examples of this include the Precision Paediatric Cancer Project (PPCP), the Challenge Research Fund, and involvement in studies with other sector leaders such as the National Child Cancer Network, Cure Kids and the Lindsay Foundation.

Being able to connect and share with other families experiencing the same challenges is an incredibly valuable resource during a child's cancer journey. CCF recognises the importance of peer-to-peer support, and creates opportunities for families to connect during and after treatment through Connect Group communities. These 22 nationwide voluntary branches are comprised of parents, caregivers, and volunteers who host regular social activities, offering mutual support and shared experiences. Families are also able to connect with each other through CCF social media groups, retreats and camps, and CCF workshops.



### Theme 3: Knowledge Creation and Knowledge Transfer

The findings of this report will provide evidence specifically for how CCF fulfills metrics from Pillars 1, 2, and 4. While this report does not focus on the outcomes of Pillar 3, the impact of CCF's investment in paediatric cancer research can be found on their website and across other publications. CCF has continued to partner with Huber Social to measure the social impact of the families they support. By funding this internal social impact measurement, CCF is gaining data-driven insights from families as to the factors they show strength and challenge in; and which drive their wellbeing throughout the different stages of their child's cancer journey.

### Theme 4: Developing Our Assets

In parallel with Pillar 1 and with the goal to support the needs of the whole family unit, CCF provides opportunity and funding for holiday homes, temporary accommodation, 'Family Places', and short-term financial support. To sustain this, CCF is seeking to develop and maintain infrastructure and resources to support families in this way.

“We look forward to putting our plan into action to help drive Child Cancer Foundation forward over the next three years and **ensure we are always working with belief, trust and empathy to support tamariki with their cancer and their whānau.**”

*-Child Cancer Foundation Annual Review, 2021-22*







# The Child Cancer Foundation **Impact Thesis**

The Child Cancer Foundation Impact Thesis outlines how the organisation's services impact CCF families. Through measuring each level of impact, CCF can use a data-driven approach to demonstrate what works and what is needed to maximise outcomes and improve overall impact.

## 1. Impact

The impact of Child Cancer Foundation is to support families with a child facing cancer to be in the best position to successfully manage their journey with cancer to maintain and support wellbeing.



## 2. Outcomes

The organisation achieves this impact by providing families with the following necessary capabilities and opportunities, including:

### Capabilities

- Community connection
- Resilience
- Life skills
- Holistic wellness

### Opportunities:

- Relationships
- Social structures
- Resources
- Self-development



## 3. Outputs

CCF delivers the following outputs:

- Families who are supported by Child Cancer Foundation services
- Families actively taking up the services, e.g. attending workshops, contacting their FSC, applying for grants, in the connect groups
- The total amount of funds distributed to families in need



## 4. Activities

These outputs are achieved with the following activities:

- An FSC to walk alongside families and provide them with emotional support and act as the main liaison with their child's treatment hospital
- Bespoke needs assessment and the delivery of respite, rest and relief, therapeutic opportunities for self-care, childcare, groceries, financial planning, budgeting and support, access to holidays, travel costs, etc.
- Social and community support, in the form of camps and retreats for siblings and parents, and the whole family events, i.e. Connect Groups
- Resilience and strength building through counselling services, grief support, shared coping strategies, Remembrance Day, etc.



## 5. Resources

The above impact requires the following inputs:

- Funding
- Physical space in Auckland and Christchurch
- CCF staff and volunteers
- Relationships with other support services e.g. medical, travel, community, education and government services



# Measurement Approach

## Design

To assess the impact of CCF services, Huber Social measures the overall wellbeing (impact) and levels of capability and access to opportunities (outcomes) of families enrolled with the organisation. To understand which outcomes were most critical for inclusion in this evaluation, a co-design workshop was first held with key stakeholders from across CCF. Since 2020, this measurement tool has been refined according to feedback from families, the CCF team and emerging needs.

## Measurement Tools and Ethical Review

Data was primarily collected through self-report surveys. Survey items used validated scales where possible; when no existing tool was appropriate, original questions were developed based on review of relevant literature and similar studies. Additional information about survey development and the full question sets can be found in the report appendix.

The CCF measurement project has approval under the Huber Social Ethical Review Board for ethical assessment (Committee No. EC00473).

## Survey Distribution and Data Collection

Online survey links were distributed by CCF via email from 1 October 2022 to 31 March 2023. Surveys were sent to families on a monthly basis as they reached key timings in their cancer journeys:

- Recent diagnosis (within the past 3 months)
- One year post-diagnosis
- Two years post-diagnosis
- Bereavement (have lost a child to cancer within the past 18 months)

In addition to the initial email distribution, a reminder was sent to families two weeks later.

## Survey Support

Introduced this year to better engage and support families with completing the survey, FSCs now offer families follow-up, technological assistance, and additional information around the purpose of measurement. According to family preference, FSCs may also be present with families as they completed the surveys to provide emotional support and/or answer post-survey queries that could arise.

## Sample Size and Response Rate

From October 2022 to March 2023, 241 surveys were distributed to CCF families, with 51 completed (21% response rate). This includes 48 responses out of 225 survey sent to families with a recent, current or former diagnosis of cancer (22% response rate) and 4 out of 16 surveys sent to bereaved families (19% response rate). Unfortunately, there were no paired responses between this and last year's measurement; this is an area Huber Social will work to improve for future studies as paired data will provide greater rigour in analysis, along with expanding data collection to include a full 12 months (April 2023 - March 2024).

These response rates mark an increase from the previous years (15% in 2021-22 and 9% in 2020). These response rates are also slightly higher than those of other studies within the paediatric cancer population. FSCs should be commended on supporting the successful collection of family responses.

*For additional information on survey development and analysis approach, see the report appendices.*

\*For example, the 2020 Red Kite's "The hidden health crisis" report surveyed approximately 3,500 families, achieving a response rate of 20%. Source: Red Kite. 2020. "The hidden health crisis: Children's cancer needs more than medicine. Australia. Available at: <https://www.redkite.org.au/news/hidden-health-crisis/>

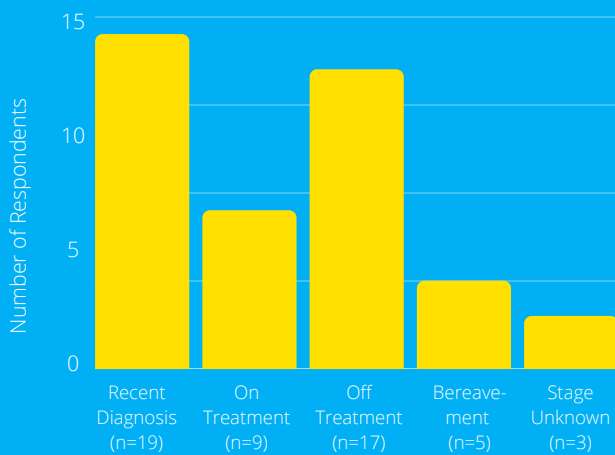


## Measurement Groups

To determine the impact of CCF services on overall wellbeing of families and key programme outcomes, survey respondents were categorized to four measurement groups for analysis:

- **Recent diagnosis:** Families with children who have received a childhood cancer diagnosis within the past 3-6 months. This group may also be referred to as 'new families' within the report.
- **On treatment:** Families with children who have been on treatment for a cancer diagnosis for approximately one year.
- **Off treatment:** Families with children who have completed their cancer treatment within the past year.
- **Bereavement:** Families who have lost a child to cancer within the past 18 months. It should be noted that due to the small sample size of this group, analysis largely focuses on that of the three other measurement groups and the sample overall.

All Responses October 2022 - March 2023, by Measurement Group



CCF Families by Journey Stage (total n=53)



# Survey Respondent Demographics

The following offers some key insights into the demographic make up of CCF's Wellbeing Survey respondents. This year just under half (46.5%) of responses are from families with children still undergoing treatment (on treatment), with just over half (51%) 'off treatment'. Similar to last year nearly all respondents (93%) are or were parents (mother/father) to a child with a cancer diagnosis.

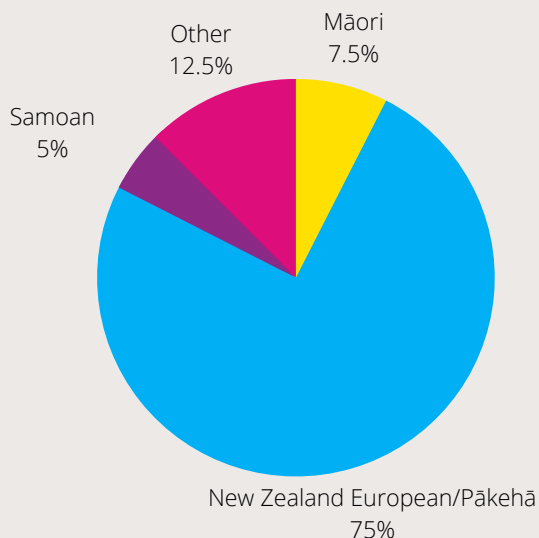
## Location

The respondents sample is largely representative of all receiving active care from October 2022 - March 2023.\* The largest difference can be seen in Christchurch (-5% underrepresentation) and Manawatu (+3%) samples, but these discrepancies are relatively minor.

## Ethnicity or Heritage

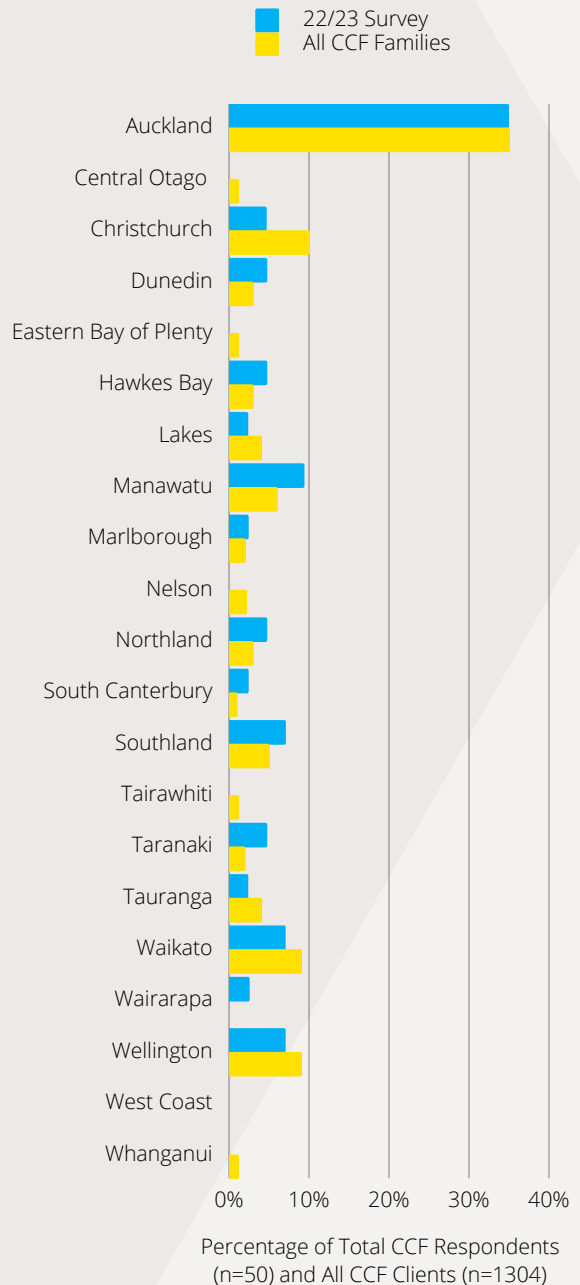
Most responses recorded were for New Zealand European/Pākehā, with 7.5% of responses identifying their children as Māori and 5% as Samoan. Other ethnicities and heritages represented include Chinese, Niuean, Vietnamese, Indian, and Tokelauan.

All Responses, by Ethnicity or Heritage of Child



\*Total CCF families includes on treatment, relapsed and bereaved families; excludes referrals.

All Responses, by Home Location of Child





*At the very beginning when we were delivered the worst news, we were sent home with this diagnosis and no support. We were overwhelmed and totally shocked with what we had been told. It was devastating and turned our lives upside down in a heartbeat. **It wasn't long before CCF got in touch and that's when we felt we had someone to talk to that knew about it all.** We are very grateful for the support given to us.*

*- 'CCF Wellbeing Survey' Respondent*



# Key Findings

The following are key high-level findings from families surveyed in 2022-23. The following sections explore these findings across CCF's strategic pillars to evidence the impact of the organisation's work.

## **1. Overall wellbeing of CCF families has been maintained since 2022**

While there was not a significant increase in overall wellbeing, there is clear evidence of CCF's support in helping families to maintain healthy levels of wellbeing by supporting families in areas most important to their wellbeing. Further data collection will help strengthen confidence in emerging wellbeing trends.

## **2. On average, CCF families are feeling more connected to other caregivers and have a greater sense of hope for the future**

These two factors exhibited a significant, positive increase compared to last year's measurements, both in families' scores as well as how much they feel CCF has helped them, suggesting that CCF's efforts are having a positive effect in families' community connection and wellness.

## **3. CCF has its greatest impact by enabling families to practice self-care and find moments of joy**

For families who have recently received a paediatric cancer diagnosis, having time and energy for self-care is a key driver of wellbeing. CCF has increased its support for families, and as a result new families reported a 300% increase in their ability to care for themselves in spite of the new challenges that they are facing.

For families with a child in remission, being able to enjoy the little things in life again can be difficult. Results show that CCF's efforts to support joy are beneficial to off treatment families in particular, as the happier and more appreciative these families feel, the stronger their wellbeing is likely to be. This year, three-quarters of off treatment families believe that CCF helps them to enjoy the little things in life, and 100% of families report having had recent moments of joy.

## **4. Encouraging connections among on treatment families offers an opportunity to maximise impact**

Having a person who can empathise with their experience was found to be particularly important for families undergoing treatment. However, almost half of respondents at this stage of their cancer journey reported not having someone in their life who understands what they're going through. This presents an opportunity for CCF to increase its positive impact for families at this stage, by encouraging and facilitating these types of connections for on treatment families.



## The **Impact** of Child Cancer Foundation

This section of the report assess the overall impact of CCF's services on families' overall wellbeing.

To understand what matters to families' wellbeing, Huber Social also measured 25 factors across five broad outcomes, looking for any significant differences compared to previous years' measurements.\* The five outcomes are:

- Healthy Relationships
- Community Connection
- Daily Life Skills
- Holistic Wellness
- Resilience

Finally, this section also examines how families' feel about their experiences with CCF and where they believe they are being most supported by the organisation.

*\*All statistical findings reported are found to be significant ( $p < 0.1$ ) unless otherwise indicated. For more information on our methodology and results, please see the appendix.*



# Overall Wellbeing of CCF Families Has Been Maintained in 2022-23

# 4.82

out of 7

**Average Wellbeing of all CCF Family Respondents in 2022-23**

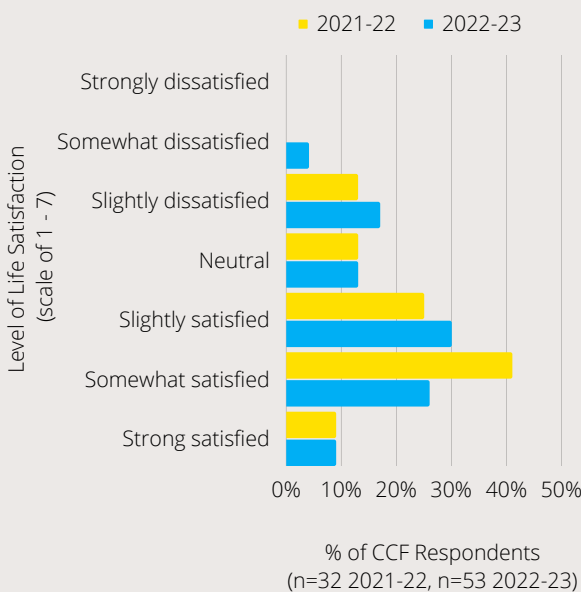
On average, CCF families feel slightly satisfied with the conditions of their life, suggesting that while families are not in protracted crisis there are opportunities to further nurture their wellbeing.

Of families who responded, two-thirds report feeling at least slightly satisfied with their life; this is a downward trend from last year's measurement, most likely attributed to bereaved families who recorded lower wellbeing scores this year.

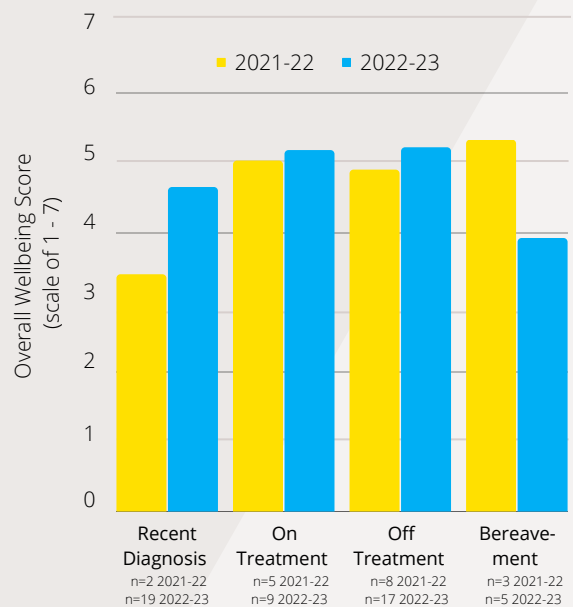
Compared to the 2021-22 measurement period, there was no significant change in overall wellbeing among families who participated in the CCF Wellbeing Survey this year\*. Wellbeing levels were maintained across each stage of the cancer journey, with initial results suggesting a potential positive trend for all excepting bereaved families.

When interpreting these results, it is important to remember that these are averages taken across groups of different families each year, families who have their own unique perspectives, characteristics and experiences. Continued collection of data, with the aim of receiving multiple measurements from the same families throughout their entire journey with CCF, will provide greater rigour in future analysis and interpretation of results.

### Distribution of CCF Families' Overall Wellbeing Scores



### Average Overall Wellbeing by Measurement Group



CCF Families by Journey Stage

\*Given the small samples sizes, particularly for measurement subgroups, statistical significance testing could not verify whether changes in overall wellbeing scores were due to sampling chance or real change (p>0.1).





# Key Progress Areas in 2022-23

## CCF Families Report Increased Caregiver Connections and Hope

Between 2022-23, there was a significant improvement in CCF families' connection to other paediatric cancer caregivers and hope for the future. While not confirmed, initial results suggest that these individual improvements extend more broadly to families' holistic wellness and community connections, both of which exhibit a potential improvement trend compared to 2021-22.



Likeminded Community

+24%

Families report having opportunities to talk to other caregivers who also have children with a confirmed diagnosis.

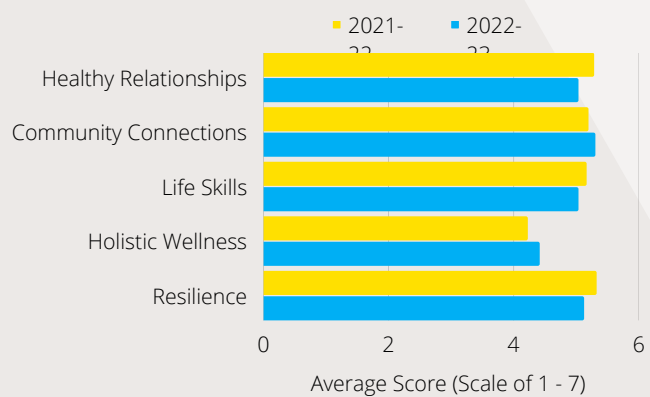


Hope for the Future

+21%

Families feel they have things to hope for.

Key Outcomes Measured, by year\*



## Increases in CCF Support Align with CCF Family Advancements

Of these highest shifts, these can be partnered with the some of the highest shifts in factors that families report CCF is offering the most support between years. This means that the areas where families are improving are well-aligned with where CCF support is being increasingly felt and having the highest impact.^

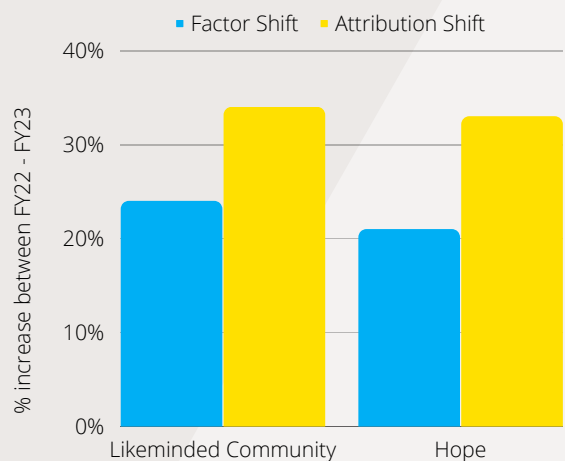
Of the shifts above, families:

- feel CCF has strongly supported them in **having opportunities to talk to other caregivers** who also have children with a confirmed diagnosis.
- feel CCF has strongly supported them to have **increase hope and optimism** for the future.

Other areas CCF are strongly supporting families across the year include:



Percentage Change in Factor and Attribution, all families



\*Note: Changes in broad outcomes were not found to be statistically significant at this time (p>0.1)

^While 'likeminded community' scores and attribution were found to be moderately, positively correlated (r=0.535, p<0.1), 'hope' scores and attribution levels do not have a statistically significant relationship at this time (p>0.1).



## Areas of Greatest Impact in 2022-23

### CCF Supports Families with A Recent Diagnosis to Practice Self-Care Strategies

With the increased resource pressures that come with a paediatric cancer diagnosis, it can be incredibly difficult for families to find the space and energy to nurture their own needs. **For families who have experienced a recent diagnosis, having the time and energy to practice self-care was found to be particularly important to their wellbeing.\***

CCF has recognised the importance of slowing down and making time for caregivers and siblings to invest in their needs, to fill their cup so that they can better support themselves and those around them. Over the past year, families across all stages of the cancer journey have reported a significant increase in CCF's support to find and act on opportunities to practice self-care.<sup>^</sup> **For families with a recent diagnosis, this increased support has contributed in part to a 300% increase in their self-care capabilities, which in turn has had a positive impact on their overall wellbeing.**

CCF should continue encouraging families to make and take opportunities for self-care, especially in the first months of a cancer diagnosis, as this is a support area where CCF can have the greatest impact on their families' overall wellbeing.

### CCF Helps Off Treatment Families to Find Moments of Joy

For families who have completed treatment, being able to enjoy life again was found to be a driver of overall wellbeing. In this year's measurement, results show that **increased feelings of joyfulness among off treatment families - and the positive impact it has on their wellbeing - can be attributed to CCF efforts.\***

**Three-quarters of off treatment families believe that CCF helps them to enjoy the little things in life, and 100% of families report having had moments of joy recently.** Both of these measures have been sustained from last year, and remain relatively high compared to all other factors measured.

CCF will want to continue supporting all families to find joy in their life in spite of the challenges they face, particularly those who have completed treatment, as these efforts are essential in helping families maintain and potentially improve their overall wellbeing.

*\*For more information on factors that drive wellbeing (predictors of wellbeing) and CCF attribution, please see the report appendix.*

*^Perceived attribution of CCF in families' self-care capabilities increased by 20% on average across all respondents in 2023 ( $p < 0.1$ ).*



# How Families Feel About Child Cancer Foundation

## Overall Satisfaction

When asked about their overall experience with Child Cancer Foundation, families were asked to rate their overall experience with CCF (positive, neutral, negative). **Over four out of five families (86%) said they have had a positive experience** with the organisation. No negative experiences were reported. Experience with CCF did not vary significantly by demographic factors nor cancer journey stage, indicating that CCF offers a positive experience to all families at every stage of their journey.

### 2022-23 Satisfaction with CCF

Total CCF Family Respondents (n=50)



For CCF to understand where families are feeling most - and least - supported families were also asked to report the level of CCF's support for each measured programme outcome. Families were asked 'how much has CCF supported you with this?'

## Overall, families are feeling most supported by CCF specifically in these areas:\*

### Relationships of Support

**3.53**

Families feel CCF provides access to relationships that offer help and support.

### Access to Support Services

**3.34**

Families feel CCF helps them access the support services they need.

### Quality Time (Children)

**3.08**

Families feel CCF supports them to have quality time with their child/children.

### Reduced Information Overwhelm

**3.13**

Families feel CCF supports them to navigate the overwhelm of the system and the amount of information around managing their child's cancer diagnosis.

### Quality Time (Support Network)

**3.17**

Families feel CCF supports them in spending quality time with others in their support network.

### Daily Life Skills (Parenting)

**3.07**

Families feel CCF supports them with the skills to care for a child who has or has had a cancer diagnosis.

\*Responses were rated on a 5-point unipolar scale from 'not at all' (1) to 'completely' (5).





## In Families' Own Words: Feeling Supported

As well as responding to questions about specific factors relating to CCF's target impact outcomes, families engaging with CCF additionally provided written feedback to describe the impact of this in their own words.\*

An emerging theme in this commentary was feeling supported and no longer feeling as alone since engaging with CCF, as evident below:

**"Keep doing what you do, because people in such a hard time need you"**

"we are not alone, we know CCF is always with us whenever we need help"

*"Helped me from not feeling so alone and unsupported"*

"It if I didn't have [CCF] **I would have been lost**"

**"It gave me a bit more hope that I'm not alone"**

*"They have been **an amazing support system** and were there for our family when we really needed them."*

**"actively made this journey less burden heavy"**

**"We have found CCF support after treatment to be most useful for us - they have directly contributed to meaningful family experiences and emotional wellbeing"**

**"Words can't even describe the gratitude I feel and the impact they have made on my life. Never will forget their help, love and kindness."**

*"Organisations like yours **really do make a difference** when families are navigating the toughest of times."*

"I'm a very strong, independent person and as a family we have adapted to this new life well. But it **has been nice knowing we have that security blanket** of the CCF if things ever get tough for us"

\*Qualitative feedback above was collected from families currently experiencing four different stages of their child's cancer journey, including children with a recent diagnosis, children on treatment, children off treatment and those experiencing bereavement.



## How Child Cancer Foundation **Creates Impact**

In July 2023, CCF announced its new three-year strategic plan. From 2022-25, the organisation will be guided by four overarching pillars, which will collectively contribute to its overall impact among the families it serves as well as the broader paediatric cancer support community. The four pillars are:

- Excellence in our Practice
- Powerful Partnerships
- Knowledge Creation and Knowledge Transfer
- Developing our Assets

This next section will examine how CCF is tracking against key performance metrics and offer insights on areas which may translate into greater impact for CCF families.



## Theme 1: Excellence in our Practice

The following section examines how CCF has worked towards achieving Theme 1 for the 2022-2023 reporting period. To understand the impact of quality service delivery across all aspects of the organisation, the following outcomes metrics will be assessed:

- **Family and Child Engagement with Key Services:** How are families interacting with and utilising CCF services and resources? Which services do CCF families find most valuable to maintaining their wellbeing?
- **Holistic Wellness and Resilience:** How does CCF help families' maintain and improve their mental, physical and emotional wellness?
- **Bereavement Support:** Where is CCF support needed most for bereaved families?





# Engagement with Child Cancer Foundation Services

CCF offers a wide range of support services for its families across all stages of the childhood cancer journey. These include practical support in navigating diagnosis and treatment, inclusion in social support networks, and access to financial and respite resources.

## Overall Access

**Over two-thirds of families surveyed reported having access to the support services they need.** This a significant increase from the previous year, and most likely due to a return to standard service delivery capacity within the organisation following the COVID-19 pandemic. Families with a recent diagnosis and those off treatment reported a slight increase in their ability to access services as compared to 2022.

Across all of CCF services provided, families feel most supported in accessing short-term financial support, wellbeing information, and FSCs; they feel least supported in accessing the Dads' Support Network and temporary accommodation.\*

## CCF Service Use

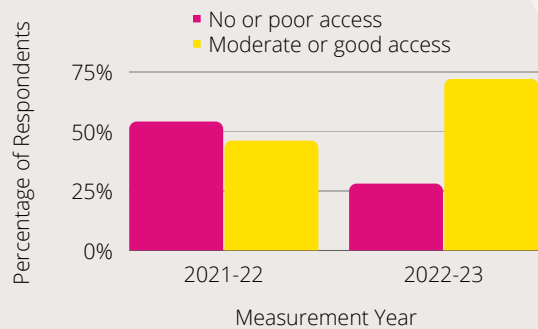
CCF families report most often utilising FSCs, wellbeing information provided, and short-term financial support. As with 2022, the Dad's Support Network, temporary housing and respite services are least utilised by families, with about one-third of respondents stating they have never used these services.

All bereaved families surveyed report having used bereavement support services offered by CCF, and that these services are at least somewhat meeting their needs.

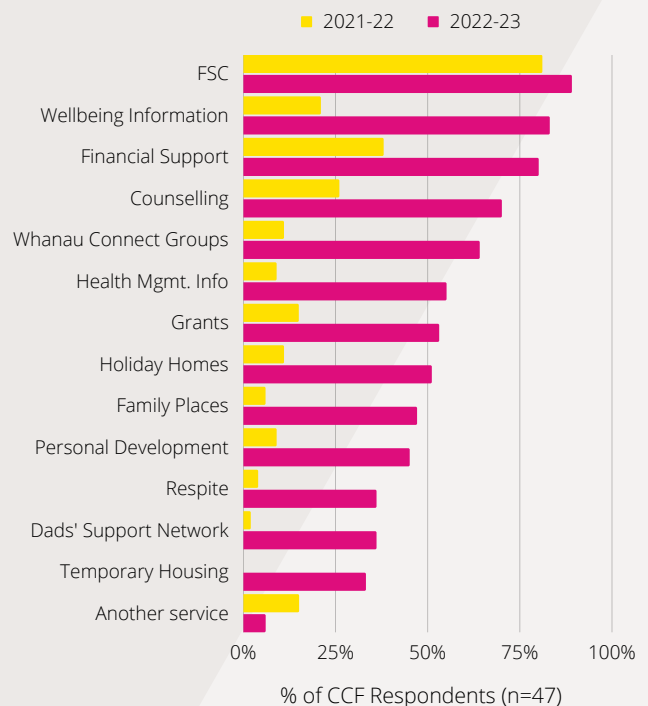
*\*Over 95% of families report that CCF has helped them to access short-term financial support, wellbeing information, and FSCs. 56% of families feel supported in accessing Dads' Support Network and 67% in accessing temporary accommodation.*

**94%** of families who responded in FY23 have engaged with CCF in the past six months or less

**Average Perceived Access to Support Services, by year**



**% Service Use of Total Respondents, by year**





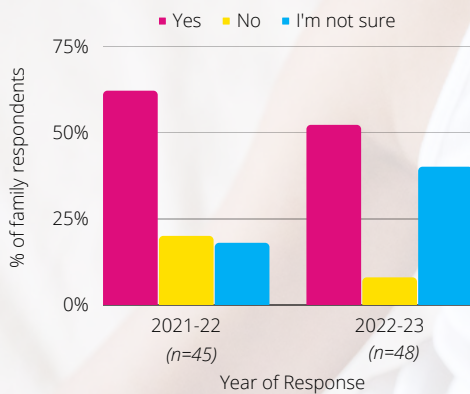
# CCF Families' Access to Counselling Services

Having access to counselling is crucial for families experiencing a child cancer diagnosis, as the service supports resilience strengthening and emotional health management.

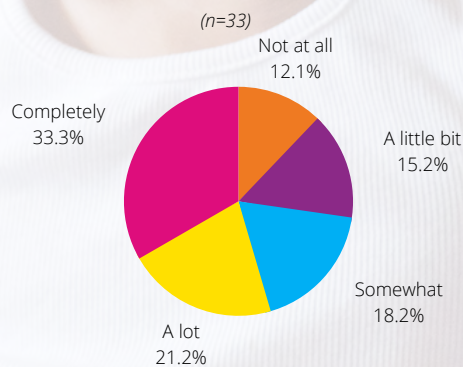
This year saw an increase in counselling service use, with 70% of respondent families reporting use of counselling services in 2022-23 compared to 26% in 2021-22. Of note, last year's impact report found that CCF families were unlikely to know how to access counselling services unless they were offered to them directly. This year's results show that, despite a smaller proportion of families being offered counselling services, on average **families feel more confident in knowing how to access counselling services if needed.**

In 2022-23, just over half of families reported being offered counselling services through CCF, compared to 60% last year. However, of those who were not offered or were unsure, 75% reported knowing how to access counselling services if needed, compared to less than 20% last year. Moreover, **of those who have used counselling services, nine out of ten families say that CCF helped them access that support** and 92% say that the services have met their needs at least a little bit, compared to 50% in last years' measurement.

**Proportion of CCF Families Offered Access to Counselling Services, by year**



**How Much Families Feel CCF Has Supported Them to Access Counselling Services**



These results suggest that, while there is an opportunity to improve initial offering of counselling services, CCF families are feeling more capable of accessing those services on their own should they need them and confident that CCF will be there to support them when they are ready to engage with counselling.

**"[CCF's] provision of psychologists and counselling have been critical to us surviving. Knowing we have support to navigate the health system is reassuring."**

-CCF Wellbeing Survey' Respondent





# Holistic Wellness

Supporting families to endure the mental and emotional challenges of a paediatric cancer diagnosis is a critical component of many CCF services, particularly the FSCs and counselling services. To assess CCF's contribution to families' mental, emotional and physical wellness, the following was measured:

- Ability to enjoy life and have hope for the future
- Changes in feelings of anxiety, anger, and helplessness
- Opportunities to maintain physical wellness and practice self-care

**On average, less than half of CCF families reported feeling satisfied with their current state of holistic wellness.** While there is no significant difference between families, initial results suggest a positive linear trend by journey stage.

Compared to last year, there was no significant change in average holistic wellness of families.\* However, it should be noted that families reported feeling significantly more hopeful; this positive change is an important contributor to families' overall wellbeing, and has likely helped to maintain wellbeing levels over the past year.

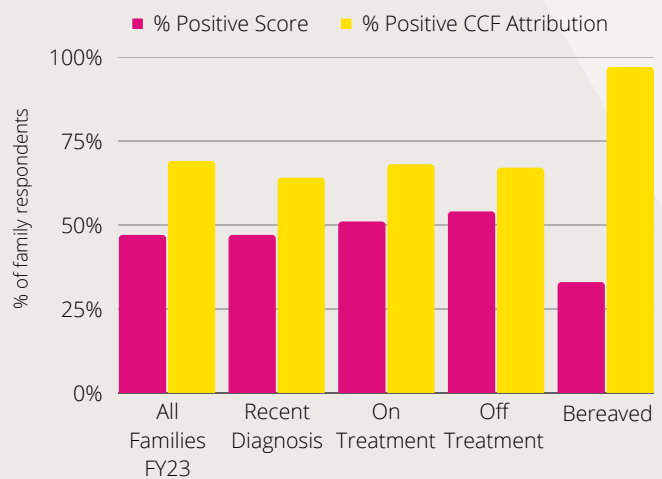
Moreover, results suggest that families feel more supported by CCF in managing their physical, mental and emotional health. Almost 100% of bereaved families report feeling that CCF has helped them to overcome negative emotions, find opportunities for exercise and self-care, and have more hope for the future.

The following page explores these findings for bereaved families in more detail.

*\*Results show that the outcome 'Holistic Wellness' increased 4% on average across all respondents compared to FY22, and that CCF support has increased by 8%; however, these results were found to be statistically insignificant (p>0.1).*

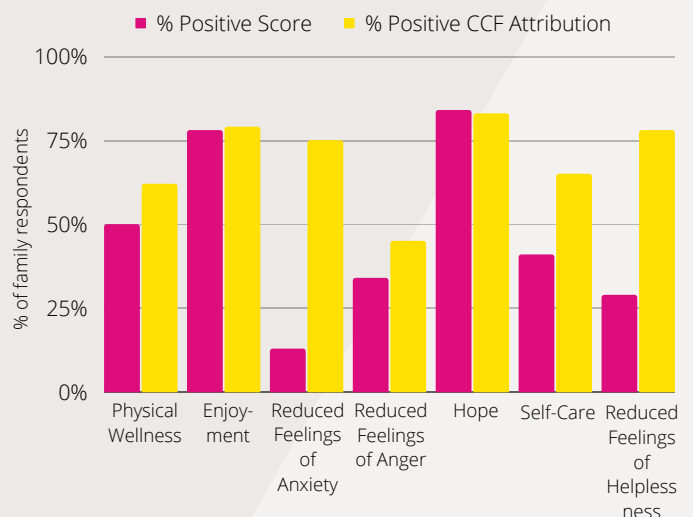
**43%** of families who responded in FY23 have positive feelings about their current wellness state

### Holistic Wellness Outcome and Attribution Scores, by stage



*Note: Bereaved families survey includes all holistic wellness metrics except 'Feelings of Helplessness' and perceived attribution of CCF.*

### Average Scores and Attributions for Holistic Wellness Factors in FY23, all families





# Inspiring Hope In Bereaved Families

The bereavement process for parents who have experienced the death of their child, at any age, is acknowledged as often the most enduring and stressful type\*. Furthermore, research on the bereavement process for parents, following the death of a child due to cancer, tells us that the process is dynamic and continuous, and that it begins before the death of the child. ^

## CCF offer bereaved families a listening ear, and hope for the future

Hope has been defined by parents who have experienced the death of a child as "essential and intrinsic to the anticipatory grief and bereavement journeys". In the previous CCF Social Impact report, 'Hope' was found to be a driver of wellbeing for bereaved families. This year, 60% of survey participants in this stage reported feeling hopeful, with 100% of families stating that CCF has helped them to maintain their hope for the future.

**100%**  
of bereaved families feel supported by CCF to remain hopeful about the future

CCF's specialised programmes for bereaved families include providing regular opportunities to connect with others who have experienced loss; families can hear how others have learned to cope, share and explore difficulties, and express and share stories to assist with their own experiences of loss. Respondents are feeling supported by CCF in having someone who will listen to them when they need to talk about their worries and problems. While only 50% of bereaved families report knowing how to access grief and bereavement services, they all believe that CCF can help them to access these services if needed.



### Supportive Relationships

100% of bereaved families have someone who will listen when needing to talk



### Knowledge of Grief Services

50% of bereaved families know of grief and bereavement services available

Additional data from this group will support further understanding of the experience of bereaved parents, and allow CCF to continue to design and deliver services that best support this group.

\*Kaye, E. C., Kiefer, A., Blazin, L., Spraker-Perlman, H., Clark, L., Baker, J. N., & Council, O. B. of the S. J. Q. of L. S. (2020). Bereaved Parents, Hope, and Realism. *Pediatrics*, 145(5). <https://doi.org/10.1542/peds.2019-2771>  
^ Polita, N. B., de Montigny, F., Neris, R. R., Alvarenga, W. de A., Silva-Rodrigues, F. M., Leite, A. C. A. B., & Nascimento, L. C. (2020). The Experiences of Bereaved Parents After the Loss of a Child to Cancer: A Qualitative Metasynthesis. *Journal of Pediatric Oncology Nursing*, 37(6), 444-457. <https://doi.org/10.1177/1043454220944059>



# Personal Resilience

All CCF families require resilience to endure the many obstacles and potential setbacks along their child's treatment journey. To assess CCF's contribution to families' resilience capabilities, the following was measured:

- Confidence in managing one's emotions
- Ability to adapt, bounce back from setbacks and avoid feeling overwhelmed
- Emotional acceptance of their child's cancer diagnosis

**On average, about two-thirds of CCF families reported feeling positive about their levels of resilience.** While this trend appears steady for most families, initial results suggest that bereaved families may have lower confidence in this area.\* This is in spite of the fact that 100% of bereaved families report feeling supported by CCF in their resiliency skills. Overall, personal resilience levels and CCF's contribution to them appear to have been maintained since FY22.^

Encouragingly, across all resilience factors the majority of families report feeling at least slightly satisfied with their personal capabilities and that CCF has supported them with these capabilities at least a little bit. Unsurprisingly, four out of five families report that CCF has helped them to emotionally accept their child's diagnosis; this is a main role of CCF and can likely be attributed to the work of FSCs and potentially other support services.

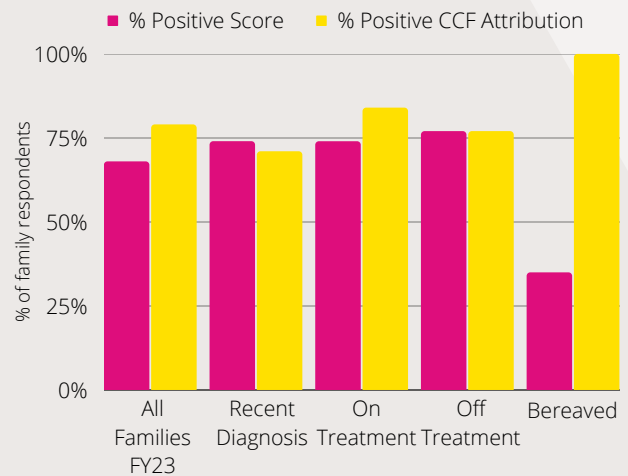
### Additional sources of resilience mentioned by families include:

- Friends, partners and whānau
- Connect Groups and FSCs
- Counselling and courses e.g., Project CALM
- Faith

*\*Due to low sample sizes, statistical testing could not confirm the significance of any potential difference in resiliency across family stage. ^Results suggest that the outcome 'Resilience' decreased 3% on average across all respondents compared to FY22, but that CCF support has increased by 8%; however, these results were found to be statistically insignificant (p>0.1).*

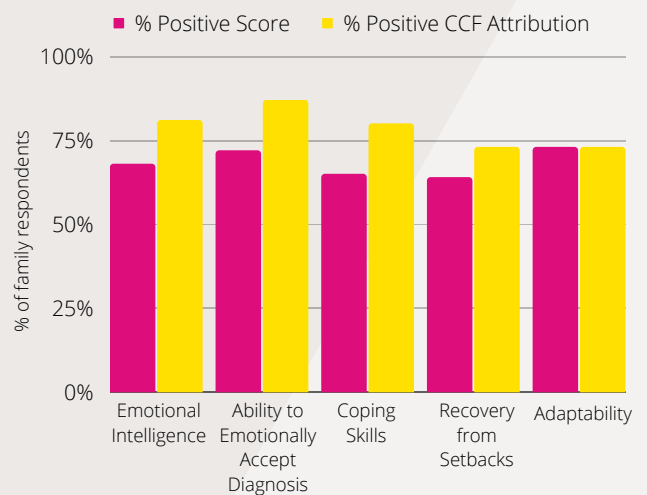
**68%** of families who responded in FY23 feel at least slightly satisfied with their personal resilience

### Resilience Outcome and Attribution Scores, by stage



*Note: Bereaved families survey includes all resilience metrics except 'Ability to Emotionally Accept Diagnosis' and perceived attribution of CCF.*

### Average Scores and Attributions for Resilience Factors in FY23, all families





# How has CCF had an impact on your life? Families' Own Words

Families consistently report, from diagnosis through to off treatment stages, that they are treated with respect by the CCF Family Support Coordinators (FSCs) working with them. This factor was the **highest scoring factor for families** across three stages in a child's cancer journey. Of all CCF support offered, families strongly attribute having people in their life who help and support them to CCF.



Respect from FSCs

**6.78**  
out of 7

Families strongly believe that they are treated with respect by their FSC

## Appreciation of FSCs

When asked "how has CCF had an impact on your life?" there was consistent commentary around the support, care and connection that CCF's FSCs provide to families, as seen below:

**"Once I met our supporter I wish I met her earlier! She is amazing. Thank you all for that."**

"my coordinator was there when I needed her, she was very empathetic"

*"The impact [from CCF] has been positive overall, the support coordinators are amazing."*

**"The support person is KEY. The right person gets you when everyone else doesn't."**

"Our Family Support Coordinator has been a very calm and supportive presence throughout this experience so far. I really enjoy talking to her. "

"The [FSC] who **has been helping me has put my mind at ease a lot.** She was there just to listen when I felt I couldn't burden my family"

**"a friendly face in uncertain times"**



## Theme 2: Powerful Partnerships

The following section examines how CCF has worked towards achieving Theme 2 for the 2022-2023 reporting period. To understand the impact of creating and maintaining powerful partnerships for families, the following outcomes metrics will be assessed:

- **Healthy Relationships:** Do CCF families have the knowledge, skills and access to support services to nurture their personal relationships?
- **Community Connections:** Do CCF families have access to communities that offer care and comfort, both within CCF and beyond? How can CCF best support families to tap into these support networks?





# Where and How CCF Families Connect with Others

With empathy as one of its core values, CCF understands the importance of having a practical support system in place during a time of crisis. The organisation offers families a wide range of opportunities to meet, share and connect with others who understand what its like to experience a paediatric cancer diagnosis.

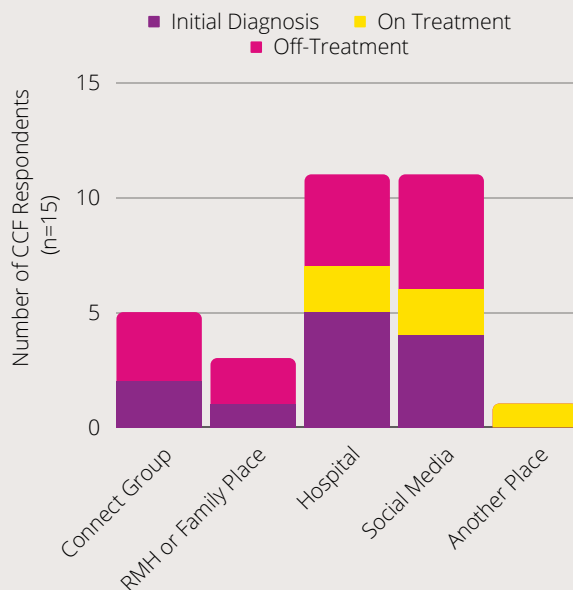
## Where CCF Connections

When completing the 2022-23 Wellbeing Survey, about one quarter of families (23%) indicated where they're connecting with others. **Majority of families who responded indicated that they connected with other families at the hospital where their children were receiving treatment (73%) and also online through social media groups (73%).** One-third of families indicated that they were connecting with others at a connect group, and one-fifth said they were connecting with others as Ronald McDonald House (RMH) or Family Place. This finding demonstrated the importance of CCF families to connect in person at hospitals as well as the support networks that are establishing online.

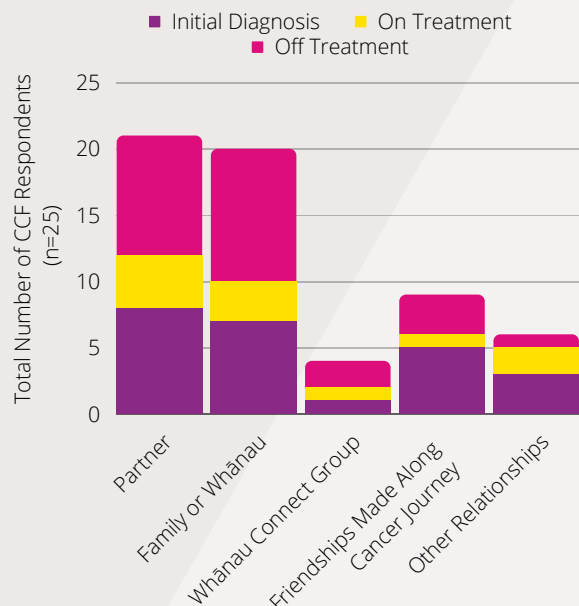
## Personal Relationships

In addition to connections facilitated by CCF, the Wellbeing Survey asked families about their supportive personal relationships. Nine out of ten of respondents cited their partner, family or whānau as a source of support. About one-third indicated friendships created during their child's cancer journey, and one-quarter indicated other relationships including friends, work colleagues, community members, and friends. While only 16% stated that friendships made through their local Whānau Connect Group were a source of support, almost 50% (49%) of respondents report they are engaged in a Whanau Connect Group through CCF this year.

Places Where CCF Families Connect, 2022-23



Supportive Personal Relationships, 2022-23





# Healthy Relationships

CCF recognises that healthy, supportive relationships are a critical component to navigating a paediatric cancer diagnosis. To assess CCF's contribution to families' relationships, the following was measured:

- Types of supportive relationships
- Ability to invest in and benefit from those relationships
- Amount CCF supports families to access supportive relationships

**On average, about two-thirds of CCF families reported feeling positive about the relationships they have in their lives.** This was highest among bereaved families, as four out of five reported feeling at least slightly satisfied with their relationships.

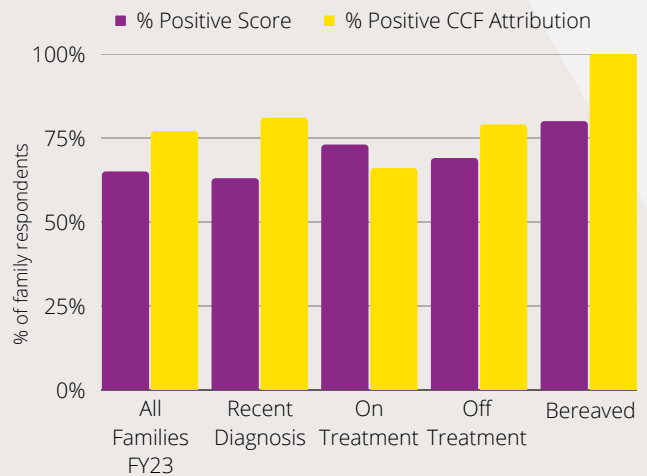
Results show that over the past measurement year there was no significant change in CCF families' access to healthy relationships nor in their perceived level of support from CCF.\* However, the majority of families do feel supported by CCF in developing healthy relationships, particularly families with a recent diagnosis and those bereaved.

**Across all healthy relationship factors measured, partner relationships appear to be struggling the most,** with less than 50% of families feeling that they have enough quality time with their partner. This challenge was identified in last year's report as well, and while it is not a main driver of wellbeing for any family stage it is still an area which could potentially benefit from additional consideration.

*\*Results show that the outcome 'Healthy Relationships' decreased 5% on average across all respondents compared to FY22, but that CCF support has increased by 14%; however, these results were found to be statistically insignificant (p>0.1).*

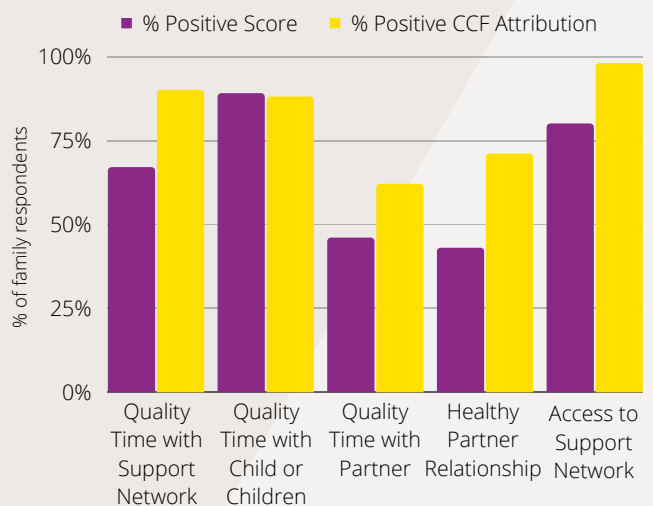
**65%** of families who responded in FY23 are at least slightly satisfied with their personal relationships


### Healthy Relationship Outcome and Attribution Scores, by stage



*Note: Bereaved families survey only includes question regarding levels of 'Access to Support Network' and perceived attribution of CCF; the other four metrics for this outcome are not included.*

### Average Scores and Attributions for Healthy Relationship Factors in FY23



A photograph of a family of three: a woman with long brown hair, a man with a shaved head, and a young child with brown hair. They are all wearing checkered shirts. The woman is standing behind the man, and the child is sitting in front of them. The background shows a window with purple curtains and a green plant.

**"[CCF had the biggest impact by] meeting with my wife. That way I knew someone, other than me was also keeping an eye on her mental wellbeing. It is a struggle to stay strong for your child and family."**

- 'CCF Wellbeing Survey' Respondent





# Community Connections

Communities provide a vital source of emotional support, shared information, and opportunities for friendship and respite. Community connections among CCF families was measured in terms of:

- Sense of connection and belonging
- Access to people who understand what they're going through and can empathise with their experiences
- Access to support services that facilitate community connection

**On average, over two-thirds of CCF families reported feeling connected to a community.**

Levels of connection were largely the same across all cancer stages. Where there was no significant change in this outcome or the perceived support from CCF, initial trends suggest that both have improved since FY22.\*

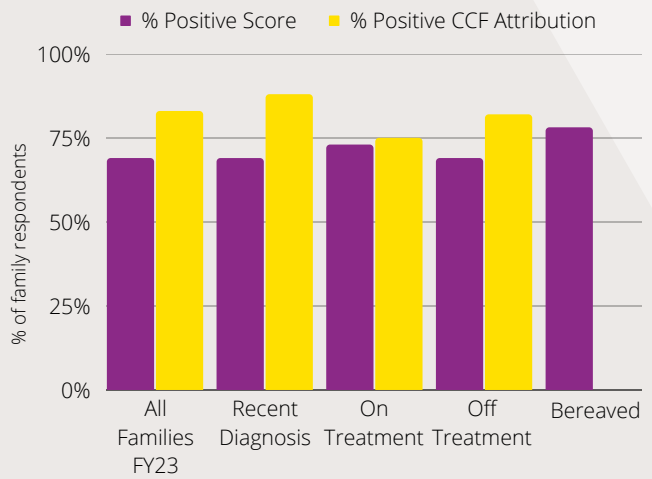
CCF should celebrate that 100% of family respondents feel that they are treated with respect by their FSC. **However, only half of families feel that they actually belong to a community.** Among families with a recent diagnosis and who are off treatment, only 50% feel that they are able to connect with other caregivers who have experienced a child cancer diagnosis.

The following page presents an opportunity for the organisation to further increase its impact on the wellbeing of families after their initial diagnosis, specifically through strengthening their access to people who understand what it is like to receive a paediatric cancer diagnosis.

*\*Results show that the outcome 'Community Connection' increased 3% on average across all respondents compared to FY22, and that CCF support has increased by 16%; however, these results were found to be statistically insignificant (p>0.1).*

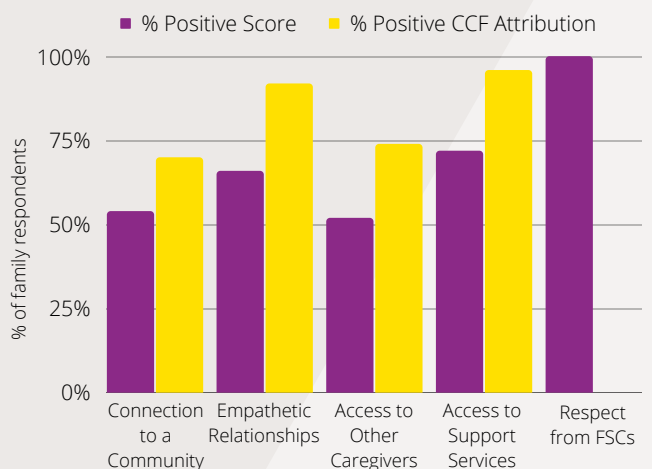
**69%** of families who responded in FY23 are satisfied with their community access and connection

## Community Connection Outcome and Attribution Scores, by stage



*Note: Bereaved families survey only includes questions regarding levels of 'Connection to a Community' and 'Empathetic Relationships' and their perceived attribution from CCF; the other three metrics for this outcome are not included.*

## Community Connection Factors in FY23



*Note: Perceived attribution for 'Respect from FSCs' was not measured*



## Opportunities for Improving Impact: Connection and Empathy

Community connection is a critical resource for all families. In particular, our research shows that **having someone to talk to who can empathise with their experience is a significant driver of wellbeing for families**, both while undergoing cancer treatment and after its completion.\*

In 2023, families reported feeling less likely to have this type of person in their lives compared to last year. **Almost half of families on treatment at the time of being surveyed reported an absence of someone in their life who can empathise with their experience (43%)**. Among families off treatment, one-third did not have a person like this.

It is understandable that forging new connections may not be a priority for families at this time in their lives. However, these types of relationships can have a positive impact on family wellbeing, and are worth creating for immediate and long-term benefits.

While CCF undertakes conscious efforts to facilitate these types of connections for families, these results suggest there may be appetite for new or additional activities for meaningful social engagement for CCF families following initial diagnosis. FSCs may also wish to reinforce the benefits of these relationships with their families, and support families to find the time and energy to invest in friendships that are more likely to nurture their overall wellbeing.

*\*'Having someone to talk to who understands what I'm going through' was found to be positively correlated with overall wellbeing for both on treatment and off treatment families. For more information on these predictor of wellbeing, see the report appendix.*





**"Our lives have only been impacted for the good from this foundation.** We are so thankful for all the information.

The cancer world can be difficult to navigate and the **Child Cancer Foundation often feels like a life preserver thrown to us when we feel we are drowning.**

Whether that be visits and conversations with our coordinator, beads of courage, massages, children's books, therapy, access to grants and other programmes for cancer families, and the Whanau connect group (just started with that one).

All have been helpful at different times when we felt we were floundering in the deep end. "

- 'CCF Wellbeing Survey' Respondent  
(Family member responded when their child is in Off Treatment stage.)



## Theme 4: Developing our Assets

The following section examines how CCF has worked towards achieving Theme 4 for the 2022-2023 reporting period. To understand the impact of developing and maintaining CCF infrastructure to support families, the following outcomes metrics will be assessed:

- **CCF families' access to holiday homes, temporary accommodation and short-term financial support:** How much has Child Cancer Foundation helped you with accessing the following services?
- **Quality of these resources as experienced by CCF families:** What is the quality of resources you have access to through Child Cancer Foundation when living away from home while your child received treatment?





# Supporting Families with Tangible Resources

Over the past year, families are showing increasing engagement with the tangible resources and assets provided by CCF. Families' access to holiday homes, temporary accommodation and short-term financial support all increased. It could be inferred that as pandemic restrictions continue to ease, families' engagement with CCF's accommodation assets will continue to rise. Financial support was one of the main ways families reported CCF supported them in 2023.

## Holiday Homes

With COVID-19 pandemic restrictions easing, this past year saw an increased number of families use CCF's service for holiday homes where over half of surveyed families engaged with this service.

## Temporary Accommodation

One-third of families reported using temporary accommodation in 2022-23; this service was not used at all last year. Generally, these families report that the quality of hospital meals, toiletries and entertainment were above average.

## Short-term Financial Support

Families reported short-term financial support as one of the top three services they access through CCF. In 2022-23, 80% of survey respondents used this service and 100% of families attributed their use to CCF's support. Qualitative findings show recurring commentary about the positive impact CCF's financial support had for families, particularly in easing the day-to-day financial strains. Contextually, this impact is important in light of post-pandemic inflation and rising living costs in Aotearoa New Zealand.

## In Families' Own Words

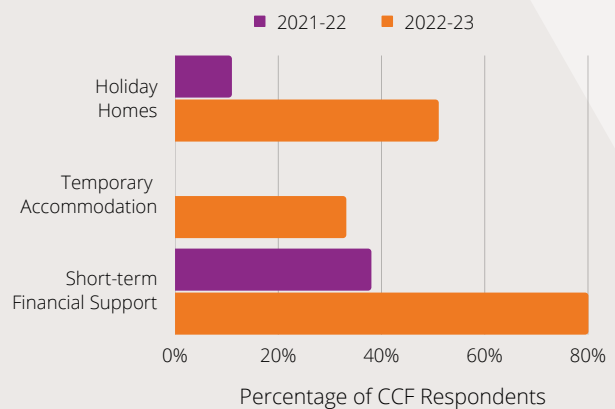
"They **have helped us heaps when struggling with money** for food and petrol. Because I had to leave my career to be a full time carer **things have been very tight so the extra help has been amazing.**"

"**Financial support** via groceries and petrol vouchers have **been life savers.**"

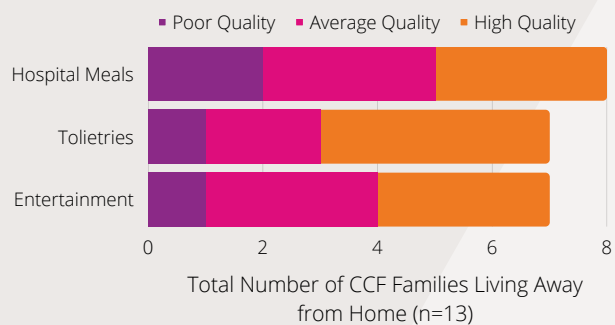
"The access to financial and mental and emotional support [through CCF] **made things 1000 times less stressful.**"

"We have found CCF support after treatment to be most useful for us - they have **directly contributed to meaningful family experiences** and emotional wellbeing."

CCF Asset Use, by year



Quality of Resources When Living Away from Home



A list of the mainservices provided and how families engaged with these over the past year can be found on page 17.



## Understanding Families' Wellbeing Needs at Each Stage of the Cancer Journey

This report itself is a symbol of CCF's commitment to its third strategic pillar of *'Knowledge Creation and Knowledge Transfer'*.

While this report does not explore specific metrics on the outcomes of Pillar 3, the impact of CCF's investment in paediatric cancer research can be found on their website and across other publications.

The following pages have been included to provide data-driven knowledge insights to specifically support Family Support Coordinators in their day-to-day support of families. Each page offers a snapshot of families' strengths, challenges, priority need/s and areas they feel most supported by CCF according to the different stages of their child's cancer journey in 2022-23: recent diagnosis; on treatment; off treatment; and those experiencing bereavement.

### Similarities and Differences Across All Stages

There are shared trends from family responses across all stages:

- CCF **families feel respected by FSCs** and feel they have the skills to support their child living with cancer.
- CCF families find **information overwhelm and feelings of anxiety consistent challenges** across all stages.
- **Feelings of anger and helplessness** are shared challenges across different stages.
- **Feeling understood and supported by others** is found to be **important for families' wellbeing** when their child is on and off treatment.
- The areas families feel most supported by CCF **differ according to stage in their child's cancer journey**.





# Child Cancer Foundation Families

## Recent Diagnosis

### Average Wellbeing

**4.65**  
Out of 7

Results below are from families three to six months after their child was initially diagnosed. Families are reporting lowest wellbeing in this stage in their child's cancer journey in comparison to their wellbeing when their child is on treatment and off treatment. At this stage, families are reporting a strong sense of hope for the future as well as the mental health obstacles of anxiousness and feeling helpless.

### Participant Strengths

High scores across the following three factors indicate areas where families have the greatest confidence at this stage:

#### Respect from FSCs Working with Child

**6.89**

Families feel they are treated with respect by the Family Support Coordinator working with their child.

#### Daily Life Skills (Parenting)

**6.12**

Families feel they have the skills to care for a child who has a cancer diagnosis.

#### Hope and Optimism for the Future

**6.00**

Families strongly feel they have things to hope for.

### Challenges Faced

Low scores across the following three factors indicate areas when families are experiencing obstacles and challenge:

#### Mental Health - Anxiety

**2.82**

Families report recent feelings of anxiousness.

#### Feeling Helpless

**3.29**

Families report feeling helpless.

#### Information Overwhelm

**3.47**

Families report feeling overwhelmed with the system and amount of information around managing their child's cancer diagnosis.

### Priority Needs

Supporting families' sense of helplessness and providing opportunities and skill-building to increase self-care are found to have a relationship with increased wellbeing. Of the challenges families are newly experiencing upon their child's recent diagnosis, these priority needs are found to have the strongest relationship with wellbeing.



### CCF Strength

Families are feeling the most supported by CCF in being able to access the support services they need.



# Child Cancer Foundation Families On Treatment

## Average Wellbeing

**5.18**  
Out of 7

Families at this stage are reporting an overall higher wellbeing score than families experiencing initial diagnosis. Supporting families' sense of belonging in a supportive community is an area to prioritise to support their wellbeing at this stage. Notably, families are reporting that CCF is strongly assisting in providing supportive relationships at this stage.

## Participant Strengths

High scores across the following three factors indicate areas where families have the greatest confidence at this stage:

### Respect from FSCs Working with Child

**6.63**

Families feel they are treated with respect by the Family Support Coordinator working with their child.

### Daily Life Skills (Parenting)

**6.13**

Families feel they have the skills to care for a child who has a cancer diagnosis.

### Personal Relationships (Children)

**6.00**

Families feel they can spend quality time with their child/children.

## Challenges Faced

Low scores across the following three factors indicate areas when families are experiencing obstacles and challenge:

### Mental Health - Anxiety

**2.88**

Families report recent feelings of anxiousness.

### Mental Health - Anger

**3.33**

Families report recent feelings of anger.

### Information Overwhelm

**3.43**

Families report feeling overwhelmed with the system and amount of information around managing their child's cancer diagnosis.

## Priority Need

Having people in their lives who understand how they feel and support their sense of belonging has a relationship with increased wellbeing and is an area to prioritise for families at this stage.



## CCF Strength

While information overwhelm remains a continued challenge, families at this stage are feeling **most supported** by CCF in these feelings of overwhelm and being supported to handle the amount of information they are receiving.





# Child Cancer Foundation Families Off Treatment

## Average Wellbeing

# 5.22

Out of 7

Families report the highest wellbeing score at this stage during life after cancer or when their child is off treatment.

A continued priority need is to strengthen families' access to a supportive and understanding community.

## Participant Strengths

High scores across the following three factors indicate areas where families have the greatest confidence at this stage:

### Respect from FSCs Working with Child

# 6.82

Families feel they are treated with respect by the Family Support Coordinator working with their child.

### Daily Life Skills (Parenting)

# 6.44

Families feel they have the skills to care for a child who has, or has had, a cancer diagnosis.

### Personal Relationships (Children)

# 6.42

Families feel they can spend quality time with their child/children.

## Challenges Faced

Low scores across the following three factors indicate areas when families are experiencing obstacles and challenge:

### Information Overwhelm

# 3.00

Families report feeling overwhelmed with the system and amount of information around managing their child's cancer diagnosis.

### Mental Health - Anxiety

# 3.07

Families report recent feelings of anxiousness.

### Feeling Helpless

# 3.33

Families report feeling helpless.

## Priority Need

Consistent with their needs when their child/ren are on treatment, access to a supportive community is a continued priority need when their child is off treatment. While this remains a low-scoring area where one-third of families off treatment do not have someone in their life who can empathise with their experience, results show that this factor saw an increase between these two stages in the cancer journey. Continuing to increase families' access to this and supporting their sense of being understood is predictive of increased wellbeing.



## CCF Strength

At this stage, families are feeling most supported by CCF in having people in their life that help and support them.



# Child Cancer Foundation Families Experiencing Bereavement

## Average Wellbeing

**3.92**  
Out of 7

Results below are from 19% of all families engaged with CCF who have lost a child to cancer within the past 18 months.^ Understandably, families are reporting their lowest wellbeing score at this stage out of all four stages measured. Despite this current wellbeing score, as previously mentioned, 60% of families experiencing bereavement reported feeling hopeful, with 100% of families stating that CCF has helped them to maintain their hope for the future. This indicates their hope for the future and what it will bring to support their wellbeing.

## Participant Strengths

High scores across the following three factors indicate areas where families have the greatest confidence at this stage:

### Relationships (Quality Time)

**6.40**

Families report being able to spend quality time with people they care about.

### Strong Family Unit

**6.00**

Families feel their family looks out for each other.

### Supportive Relationships

**5.80**

Families feel have people who help and support them.

## CCF Strengths at this Stage

When experiencing bereavement, families report CCF has most assisted in these three areas:

### Supportive Relationships

CCF has helped families have someone who is there when they want to talk about worries or problems.

### Information Network Support

CCF has helped families know of grief and bereavement support services.

### Providing Hope

CCF has helped families with increased hope for the future.

## Challenges Faced

Low scores across the following three factors indicate areas when families are experiencing obstacles and challenge:

### Mental Health - Anger

**2.00**

Families report recent feelings of anger.

### Mental Health - Anxiety

**3.00**


Families report recent feelings of anxiousness.

### Connection with Healthcare Team

**3.00**

Families report they have limited contact with the healthcare team that care for their child.

^Data collected is from five families who have lost a child from cancer in the last 18 months. The low sample size means the outcomes should be interpreted with caution when relating to all families experiencing bereavement. Further, the lack of longitudinal data for these families means we are further limited in our understanding of the shifts in wellbeing and outcomes that occur for families who progress to this stage.

A photograph of a man and a young boy walking together in a grassy field. The man is on the left, wearing a checkered shirt and shorts, with a white shirt draped over his shoulder. The boy is on the right, wearing a black tank top and blue shorts, with a bandage on his knee. They are both looking down at the ground. The background is a blurred green field with some buildings in the distance.

"Thank you so much for all that you do to help and support families like mine. Organisations like yours **really do make a difference when families are navigating the toughest of times.**"

- 'CCF Wellbeing Survey' Respondent  
(Family member responded when their child is in On Treatment stage.)

"I'm very grateful for the work CCF does for my family. They **actively made this journey less burden heavy** and I know from experience that they will do all they can to help you."

- 'CCF Wellbeing Survey' Respondent  
(Family member responded when their child is in On Treatment stage.)



# Get in Touch



## Child Cancer Foundation

[info@childcancer.org.nz](mailto:info@childcancer.org.nz)  
[www.childcancer.org.nz](http://www.childcancer.org.nz)



## Huber Social

[info@hubersocial.com.au](mailto:info@hubersocial.com.au)  
[www.hubersocial.com.au](http://www.hubersocial.com.au)





## Appendices:

- The Huber Social Wellbeing Measurement Framework
- Data Transparency Page
- Analysis Approach and Results
- CCF Wellbeing Survey Development
- Question Sets



# Huber Social Wellbeing Measurement Framework

To be able to fulfil their potential and achieve wellbeing, each individual needs to have the capability and the opportunity to do so. Everyone has different needs within these categories depending on their context.

When it comes to measuring the social impact of a service, Huber Social measures the 'shift' the service creates in terms of wellbeing and the specific outcomes achieved to create this. Results are then consolidated at a sector, community and global level.

Longitudinal measurement monitors effectiveness of programs, projects or initiatives to meet these needs; ensuring resources are directed to have the greatest impact. The vision is a wellbeing measurement system that delivers the whole picture, to put each of us in the best position to achieve wellbeing and leave no one behind.

**The goal for each of us is the same; wellbeing. That which differs are our individual needs.**

## The Huber Social Wellbeing Measurement Framework

IMPACT

### Wellbeing

To be in the best position to fulfil your potential and live a life of value. The overall goal for all services working with people.

OUTCOMES

#### Through building Capability

Resilience  
Life skills  
Wellness - mental, physical and spiritual

OUTCOMES

#### and providing Opportunity

Resources  
Self development  
Societal structures  
Relationships



# Data Transparency Page

To support understanding of the findings and informed decision-making, Huber Social includes a data transparency page for every measurement project. This makes clear the rigour of evidence and analysis across every stage of the data lifecycle for the measurement project.



Phase	Questions on the Treatment of the Data	Points allocated	Yes or No	
<b>Design</b>	Everyone in the intervention included in the measurement	2	N	
	SAMPLE OR Survey sample population designed to be representative of group	1	Y	
	Sample description: <i>Surveys were distributed to 241 families between October 2022 and March 2023. 51 surveys were completed for a 21% response rate.</i>	N/A	N/A	
	BASELINE Control group (independent of the intervention)	3	N	
	Group baseline measured (pre -intervention)	2	N	
<b>Data Collection</b>	BASELINE Baseline inferred from time in intervention (e.g., 1 vs. 3 years)	1	Y	
	EXCLUSIONS Details of people specifically excluded from the measurement: <i>Surveys were distributed only to families based on selection criteria (had received a diagnosis within the past 3 months, 3year post-diagnosis, 2years post diagnosis).</i>	N/A	N/A	
	DISTRIBUTION	Online surveys		Y
		OR hardcopy surveys		N
		Data collection supervised by Huber Social consultant	1	N
DATA SOURCES	Translation or guidance provided	N/A	N/A	
<b>Cleaning</b>	Data mining of other sources	1	Y	
	Data included from previous years/measurements	1	Y	
	Details of additional data sources: <i>Sample demographics compared to CCF records to assess for generalizability of results. Completion rates compared to that of pilot year's collection.</i>			
	CLEANING Partial responses removed or no partial responses	1	Y	
	Details of any responses removed: <i>Partial responses removed if missing &gt;50% Satisfaction with Life Scale data and/or &gt;50% of outcomes data.</i>	N/A	N/A	
<b>Analysis</b>	SHIFT MEASUREMENT Calculated on time in intervention		Y	
	Calculated on group average	1	Y	
	Calculated based on individual scores	2	N	
	TEST APPLIED	Basic analysis		Y
		Statistical Correlation Test	2	Y
Multiple Regression or Lasso Regression Test		3	N	
<b>Reporting</b>	REPORTING Client published Outcomes Report (prove)	1	N	
	Client received Social Performance Report (improve)	2	Y	
	Client published full Social Impact Report	3	Y	
<b>RIGOUR SCORE</b> LOW: 1-9; MED 10-14; HIGH 15-19		<b>MED</b>	<b>13</b>	



# Analysis Approach and Results

The Huber Social Wellbeing Measurement Framework sets out to measure the impact of organisations' interventions. It achieves this by measuring (1) the overall wellbeing of programme participants (CCF Families) by measuring subjective wellbeing using the SWLS, and (2) the relevant capabilities and access to opportunities (outcomes) necessary for a person to be in a position to achieve wellbeing. To understand the impact CCF has on families' overall wellbeing, the outcomes measured are directly aligned to those of the programme; the final tool includes 25 factors measuring five broader outcomes.

Correlation analysis (Pearson or Spearman's, as appropriate) is then used to identify which factors have a significant correlation with overall wellbeing, positive or negative. It can then be inferred that, for outcomes which are positively correlated with overall wellbeing, an increase or improvement across those factors is more likely to accompany an increase or improvement in overall wellbeing. These factors are called 'predictors of wellbeing'.

To assess the level of attribution of CCF to improvements in families' overall wellbeing (the impact), studies would typically rely on a control group. Given the practical and ethical limitations of including a control group in this study, the question was instead directed to survey respondents. For each factor question asked, CCF families were also asked to reflect on and rank how much they felt that CCF was responsible for their status with respect to that factor.

Basic statistical analysis created an indication of the average level of CCF attribution for each programme factor. Correlation analysis was then applied again to understand which factors measured were significantly correlated with their relative attribution metric. Factors that were both positively correlated with wellbeing and with CCF attribution suggest a direct statistical relationship between CCF services and overall wellbeing. In other words, when CCF support increases, this factor is more likely to increase as well, which in turn is likely to contribute to improved overall wellbeing.

In this report, predictors of wellbeing have been identified for all CCF families, both of the sample overall as well as among families at key stages of their cancer journey. On the following page, Table 1 lists all predictors of wellbeing, along with their relative outcomes score, attribution score, correlation coefficient, and significance level (p-value). Table 2 lists all factors significantly correlated with their CCF attribution score. An asterisk (\*) indicates a factor which is both positively correlated with wellbeing, and where CCF attribution is also positively correlated with that factor. These relationships suggest that when CCF support increases, this factor is likely to increase as well, which in turn is likely to contribute to improved overall wellbeing.





# Analysis Approach and Results

**Table 1. All Predictors of Wellbeing (Factors Correlated with Wellbeing)**

All predictors of wellbeing, along with their relative outcomes score, attribution score, correlation coefficient, and significance level (p-value).

Factor	Stage	Average Score (out of 7)	Attribution Score (out of 5)	Correlation Coefficient	p-value
Financial literacy	Recent Diagnosis	5.67	2.47	0.656	p<0.005
Access support services needed	Recent Diagnosis	5.27	3.56	0.471	p<0.05
Reduced feelings of helplessness	Recent Diagnosis	3.29	2.42	-0.403	p<0.1
Time and energy to look after oneself	Recent Diagnosis	4.18	2.32	0.388	p<0.1
People in one's life who understands how one feels	On Treatment	4.57	3.00	0.588	p<0.1
	Off Treatment	5.62	2.94	0.431	p<0.1
Moments of Joy	Off Treatment	6.25	3.06	0.448	p<0.1



# Analysis Approach and Results

**Table 2. All Attribution Factors**

All factors significantly correlated with their CCF attribution score.

Factor	Stage	Average Score (out of 7)	Attribution Score (out of 5)	Correlation Coefficient	p-value
Financial literacy	Recent Diagnosis	5.67	2.47	-0.467	p<0.1
Having the opportunity to maintain physical wellness	Recent Diagnosis	4.88	2.05	-0.425	p<0.05
Reduced feelings of anger	Recent Diagnosis	4.15	1.63	0.382	p<0.01
	Off Treatment	4.90	2.00	0.422	p<0.1
Feeling connected to a community	On Treatment	4.60	1.57	-0.819	p<0.01
People in one's life who help and support them	Off Treatment	5.62	3.76	0.431	p<0.1



# CCF Wellbeing Survey Development

Data for this report was primarily collected through self-report surveys completed by all participants. Two surveys were used: (1) Family Wellbeing Check 2023 and (2) Family Wellbeing Check (Bereavement) 2023. The Bereavement survey measures slightly distinct outcomes as opposed to the general Family Wellbeing Check, and does not ask the same demographic and diagnostic questions as the general survey.

## Survey Development

These surveys are developed based on the agreed scope of measurement in the Child Cancer Foundation Social Impact Thesis, and designed to measure the indicators identified in the Impact Thesis. The survey contains five types of questions:

- Demographic questions, including details regarding cancer diagnosis, length of treatment, etc.
- Subjective wellbeing questions, as measured using the Satisfaction with Life Scale (SWLS).
- Programme outcomes questions, mostly measured on a 7-point bipolar Likert scale of agreement from 'strongly disagree' (1) to 'strongly agree' (7) with a few questions based on a scale of frequency.
- Attribution questions, to help ascertain the amount of change attributable to CCF. These questions accompany each programme outcome question, and are based on a 5-point unipolar Likert scale from 'not at all' (1) to 'completely'.
- Open ended feedback, to gather qualitative insights into particular aspects of CCF service delivery.

With the exception of the SWLS, all survey questions were developed by Huber Social with input from CCF.

To enable longitudinal study of families' journeys with CCF while still maintaining deidentification of results, unique IDs were assigned to each family with receipt of their survey. Future data collection will hopefully allow for analysis of paired responses in addition to group-level.

## The Satisfaction with Life Scale

To measure overall wellbeing, survey respondents were asked to reflect on and rate their satisfaction with life, using the SWLS. In the pilot measurement, the SWLS was included in its original format in the 2020 CCF Wellbeing Survey.

However, in the 2021-22 measurement scale items were re-worded to be in a reversed direction of positivity. For example, the item 'I am satisfied with my life' became 'I am not satisfied with my life.' It was believed that it would be more acceptable for CCF families to reflect on and rate their satisfaction with life if the items were in this format; however, it does mean that this year's responses are not comparable to the pilot data.

## Survey Testing and Validation

To ensure the survey questions are culturally, linguistically and ethically appropriate, and that all survey questions are understood by participants, surveys are tested and validated with select individuals from the measurement group before rolling out to the entire sample. Survey piloting was completed in the pilot measurement, but has not been repeated for subsequent measurements.

