

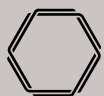


# Child Cancer Foundation Social Impact Report 2024

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

May 2024

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 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 Aotearoa, which underpin our understanding of wellbeing and how it is measured.

Data was collected across Aotearoa New Zealand.



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## Disclaimer

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# Walking alongside tamariki and their whānau on their cancer journey

Having a child diagnosed with cancer can change a family's world forever. Child Cancer Foundation walks alongside children and their families every step of the way as they navigate the challenges of their cancer journey.

Each family's experience is unique, and so is the nature of the support they need as they adapt to their new reality. Child Cancer Foundation supports families by focusing on the whānau, not the cancer. They provide personalised support specific to each family's needs, helping to lighten the load in the areas that will help them the most. This may include, but is not limited to, support with finances, finding ways to overcome day-to-day challenges, managing emotions, maintaining healthy relationships, and finding connection with a supportive community of people who understand their experiences.

This support can make a significant difference in helping families to move forward, maintain control of their lives, and focus on what matters most - loving and caring for their child.

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 available to support them at a time when they need it most.

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 enhance the empirical evidence of its impact and facilitate the execution of their mission, CCF has collaborated with Huber Social to develop a measurement system capable of both measuring and maximising its social impact.

Huber Social has been measuring the impact of CCF since 2020, with the design and delivery of programs continually leveraging insights and lessons from previous years. Huber Social supports CCF to achieve their vision through measurement which informs internal decision making, strengthens support from donors, and identifies opportunities to collaborate with others. Its measurement methods and reports adhere to accounting standards, ensuring transparency and reliability.



# Why Measure Social Impact?

This is Child Cancer Foundation's fourth 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 provides 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.



*\*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 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.

*“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*

**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), and involvement in studies with the NCCN registry.

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 19 nationwide voluntary groups 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, 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, and short-term financial support. To sustain this, CCF is seeking to develop and maintain infrastructure and resources to support families in this way.







# 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.

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## 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.

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## 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
- 



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## 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
- 



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## 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 a 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, i.e. Connect Groups
  - Resilience and strength building through counselling services, grief support, shared coping strategies, Remembrance Day, etc.
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## 5. **Resources**

The above impact requires the following inputs:

- Funding
  - Physical space in 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 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 April 2023 to 31 March 2024. 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 email was sent to families two weeks later.

## Survey Support

To engage and support families with completing the survey, FSCs offer families follow-up consultations, technological assistance, and additional information around the purpose of measurement.

Depending on family preference, FSCs may 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 March 2023 to April 2024, 403 surveys were distributed to CCF families, with 75 completed (19% response rate). This includes 70 responses out of 379 survey sent to families with a recent, current or former diagnosis of cancer (18% response rate) and 5 out of 24 surveys sent to bereaved families (21% response rate).

The CCF Annual Impact Report measures the impact of CCF on families across the year. In doing so, analysis looks at the measurement groups combined as the CCF community, as well as individually to gain an understanding of each stage. CCF endeavours to undertake a future longitudinal analysis that will investigate the impact of CCF on families across the years. This will allow the pairing of data to understand the impact of CCF on individual families across their journey.

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

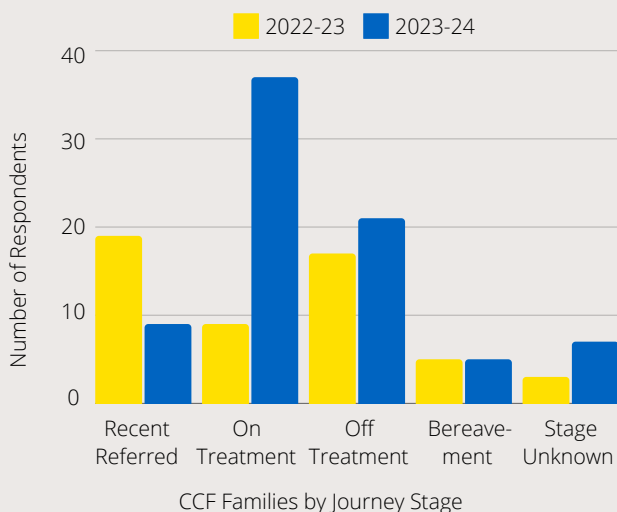


# Measurement Groups

Measurement in 2023-24 included a total of 79 families. This is a 49% increase compared to 2022-23 measurement which included a total of 53 families. To determine the impact of CCF services on overall wellbeing of families and key programme outcomes, survey respondents were categorised to four measurement groups for analysis:

- **Recently referred:** Families who have recently been referred to Child Cancer Foundation within the previous 3 months. This group typically includes 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 by Measurement Group





# 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 (47%) of responses are from families with children still undergoing treatment (on treatment), with just over a quarter (27%) being 'off treatment'. Across April 2023 - March 2024 CCF had active engagement from 337 families. Measurement this year included 79 families, representing 23% of the CCF engaged community across this measurement year.

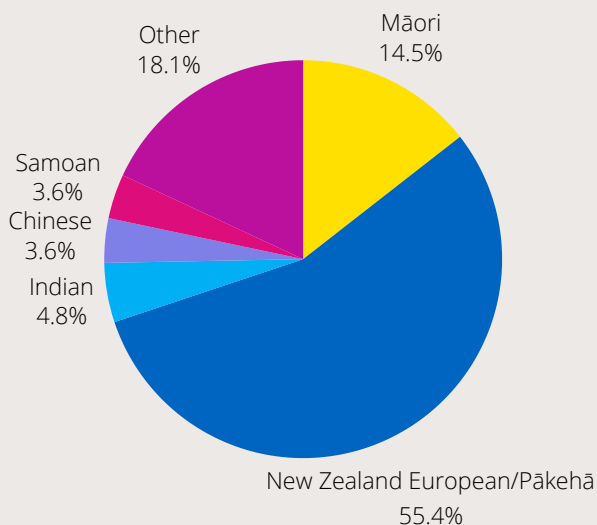
## Location

The respondents sample is largely representative of all receiving active care from April 2023 - March 2024.\* The largest over representation is seen in Wellington (+7%) and Waikato (+4%) and the largest under representation is seen in Auckland (-11%) and Wairapapa (-7%), but these discrepancies are relatively minor.

## Ethnicity or Heritage

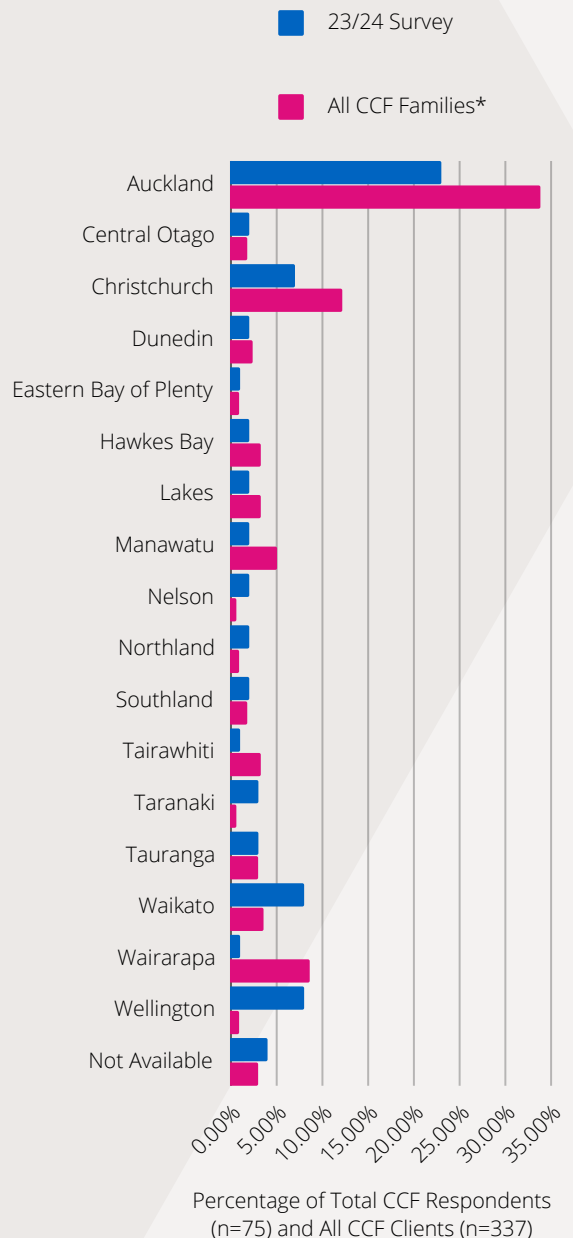
Most respondents (parents/guardians) identified as New Zealand European/Pākehā (65.96%), follow by Māori (9.8%) and Chinese (5.88%). Other ethnicities and heritages represented included, but were not limited to, Indian, Niuean, Dutch, Japanese, and Tokelauann.

All Responses, by Ethnicity or Heritage of Child



\*Total CCF families includes all families engaged with CCF across March 2023 - April 2024, excluding referrals.

## All Responses, by Home Location of Child





## How Families Feel About Their Child's Cancer Journey

Cancer treatment for children is an individual journey and is specific to each child's specific cancer type, genetics, and health. This results in diverse experiences and outcomes. Treatment plans, including surgery, chemotherapy, radiation, and immunotherapy, vary by individual factors. As such, children may face different ongoing symptoms and, at times, late effects.<sup>1</sup> Late effects are problems caused by cancer treatment that may not show up for months or years after treatment.

37.5% of families reported that their child has experienced ongoing symptoms due to the cancer treatment. Included are symptoms of ongoing sinusitis issues, nose bleeds, chronic fatigue, brain fog, fear, tiredness, sore eye, weakness, trouble with legs, low immunity, and poor appetite.

Despite these challenges experienced by the children, 86.54% of families feel their child's cancer treatment is progressing as planned. This demonstrates the significant level of trust and satisfaction in the healthcare system's ability to manage and address their child's specific needs.

***"[CCF] have given me tools to support myself, my whānau and my princess through this journey. Supporting us all by letting us take this journey at our own pace and providing pockets of hope, peace, comfort, reassurance and care throughout."***

- 'CCF Wellbeing Survey' Respondent  
(On Treatment stage, not pictured)





*“CCF has helped us to **feel supported and heard** through something we never thought would happen to our child and us as a family. **Both the physical and financial support we received was so much help**, and having someone who has experienced what we are going through makes a huge difference...*

***Out of all the help and support we have received up to this point, the best and most helpful has come from the Child Cancer Foundation. I honestly believe if we had not had your support, this last year would have been so much harder.”***

*- 'CCF Wellbeing Survey' Respondent  
(not pictured)*





# Key Findings

The following are key high-level findings from families surveyed in 2023-24. 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

While there was not a significant increase in overall wellbeing, there was a trend for wellbeing to improve from last year. Further, there was clear evidence of CCF's commitment and contribution to supporting family wellbeing by addressing the areas most important to their wellbeing. Ongoing data collection will further solidify our understanding of emerging wellbeing trends.

## 2. On average, CCF families reported feeling less overwhelmed with greater access to support services

Families were feeling the most supported by CCF in connecting them to support services they feel they need. This is evident through increased access to support services, compared to last year, coupled with reduced feelings of being overwhelmed by information about managing their child's cancer diagnosis. These improvements underscore the effective and supportive role CCF plays in assisting families.

## 3. Encouraging healthy partner relationships among families offers an opportunity to maximise impact

Healthy partner relationships are vital for emotional support, strengthening familial bonds and coping mechanisms. However, across all families, maintaining healthy partner relationships was found to be a priority need, being both a predictor of wellbeing and scoring relatively low compared to other predictors. CCF is already showing great support in this area, particularly with families who have a child on-treatment. However, these results highlight the importance of these relationships and presents an opportunity for CCF to increase its positive impact for families, by further encouraging and facilitating these types of connections.

## 4. CCF supported bereaved families in their resilience

Resilience plays a vital role for parents navigating the loss of a child to cancer, facilitating their psychological adjustment and journey toward healing beyond this profound loss. This year, bereaved families showed an increase in adaptability to unexpected events and in their ability to recover quickly from setbacks, both which were reported to have great support from CCF.



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

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

To understand what matters to families' wellbeing, Huber Social 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 2023-24

# 5.11

## Scale of 1-7

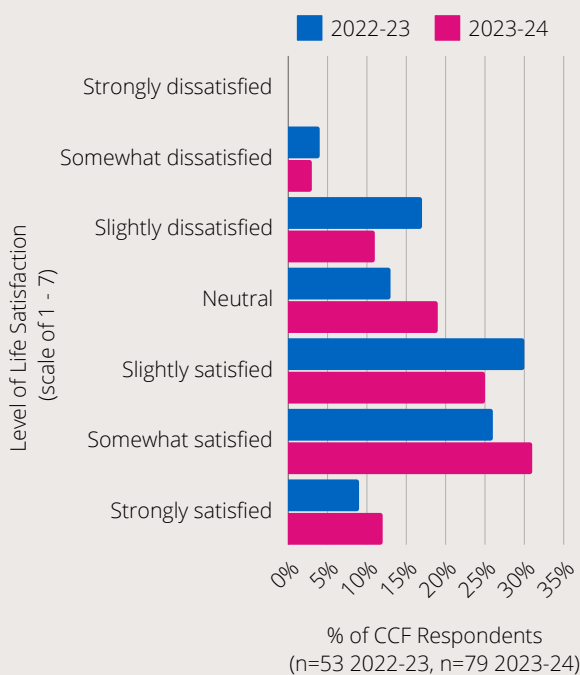
**Average Wellbeing of all CCF Family Respondents in 2023-24**

In the 2023-24 measurement, CCF families reported an overall wellbeing score of 5.11 (scale of 1-7). This score represents that on average families are feeling somewhat satisfied with their lives, compared to last year's measurement when on average families reported feeling slightly satisfied, with an overall wellbeing score of 4.82 (scale of 1-7). While this is not a statistically significant change, the results suggest a trend for wellbeing to improve, which may be confirmed with future measurement with a larger sample size.

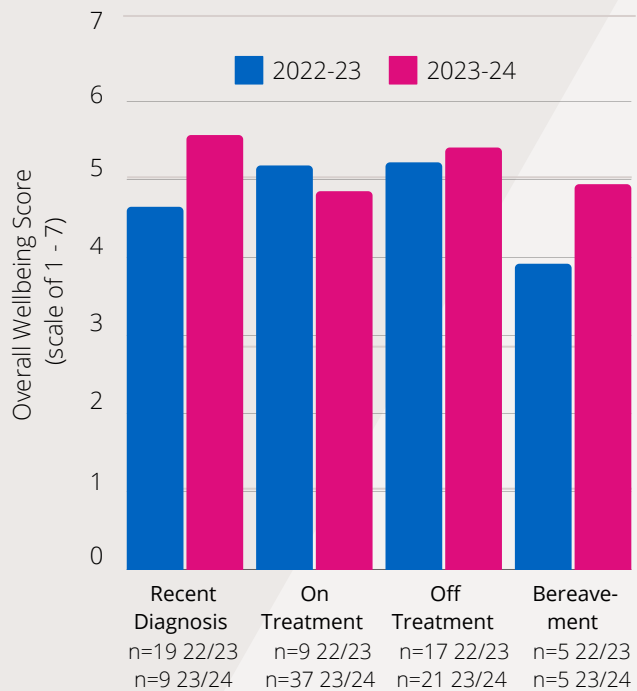
Wellbeing levels were maintained across each stage of the cancer journey, with overall wellbeing scores for three out of the four measurement groups being higher this year compared to last year's results. Encouragingly, families experiencing bereavement reported an increased overall wellbeing score this year, after recording lower wellbeing scores in the 2022-23 measurement period.

When interpreting these results, it is important to be aware of the limitations of the small sample sizes, and to also note that measurement has been conducted with different groups of families each year. Future longitudinal measurement, with the aim to collect data from the same families across the years as they move through different stages of their cancer journey, will allow for further strengthening of these results.

**Distribution of CCF Families' Overall Wellbeing Scores**



**Average Overall Wellbeing by Measurement Group**





## Areas of Greatest Impact in 2023-24

### CCF Supports Families On-Treatment to Spend Quality Time with Their Partners

Quality time between partners who have a child undergoing cancer treatment is important as it provides emotional support, strengthens familial bonds, and improves coping mechanisms. Shared experiences and mutual support further help mitigate stress and enhance resilience, leading to better psychological outcomes for the entire family.<sup>2-3</sup>

This year, families on-treatment were found to feel a +16%<sup>^</sup> greater struggle in their relationship with their partner due to the pressures they are under from their child's cancer diagnosis. This coincides with **families reporting a +24%\* increase in the support they are receiving from CCF to help them spend quality time with their partners.**

CCF should continue encouraging families to make and take opportunities to spend quality time with their partners, especially during their child's treatment period, which can be a challenging period with increased support needed towards the child's care.

### CCF Supports On-Treatment Families to Connect with Their Community

Connecting with the community is essential for families navigating pediatric cancer treatment, offering emotional, social, and practical support. Community involvement further reduces stress and enhances coping abilities for both the child and their family.<sup>4</sup>

**On-treatment families this year reported a +13%\* increase in the support from CCF to connect with their community.** This increase in support was coupled with a trend for families to feel +9%<sup>^</sup> more connected with their community compared to last year.

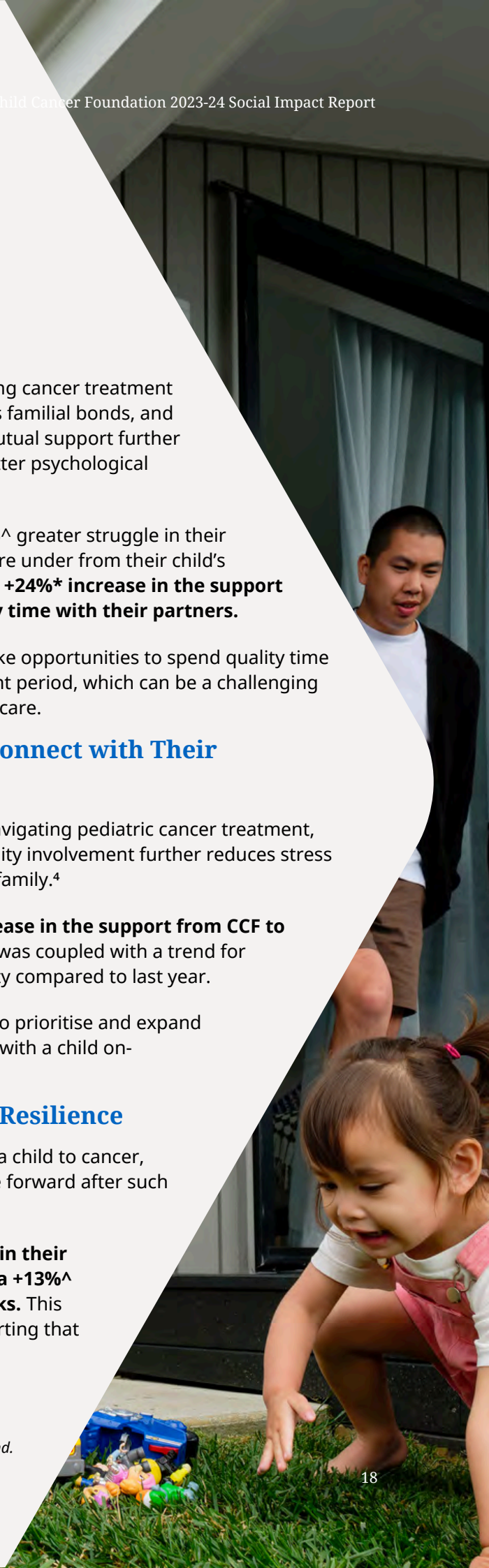
Given the positive impact observed, CCF should continue to prioritise and expand its efforts to facilitate community connections for families with a child on-treatment.

### CCF Supports Bereaved Families in Their Resilience

Resilience is important for parents coping with the loss of a child to cancer, helping them adapt psychologically and find ways to move forward after such a profound loss.<sup>5</sup>

**Bereaved families this year reported a +42%\* increase in their ability to adapt when unexpected events happen, and a +13%<sup>^</sup> increase in their ability to recover quickly after setbacks.** This coincides with 100% and 75% of families respectively reporting that CCF helps them in these areas, respectively.

*\*Indicates a finding that is statistically significant ( $p < 0.01$ ) meaning we are confident that 99% of the time an observed difference in these factors is true.  
<sup>^</sup>Findings are not statistically significant ( $p > .01$ ), however they indicate a trend.*





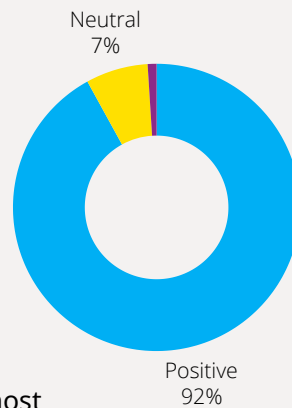
# How Families Feel About Child Cancer Foundation

## Overall Satisfaction

When asked about their overall satisfaction with Child Cancer Foundation, families were asked to rate their experience as positive, neutral, or negative. Feedback was exceptionally positive, with **92% of families reporting a positive experience with CCF**. Overall satisfaction with CCF did not significantly differ across demographic factors nor cancer journey stage, indicating that CCF offers a positive experience to all families at every stage of their journey.

### 2023-24 Satisfaction with CCF

Total CCF Family Respondents (n=76)



To understand where families are feeling most supported by CCF, respondents were also asked to report the level of CCF's support for each measured programme outcome. Families answered the question 'how much has CCF helped you with this?'

## Overall, families are feeling most supported by CCF in the following areas :

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

### Access to Support Services

**3.32**

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

### Relationships of Support

**3.32**

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

### Feeling Understood

**2.90**

Families feel CCF supports them to have people in their lives who understand how they feel.

### Reduced Information Overwhelm

**2.87**

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

### Daily Life Skills (Parenting)

**2.83**

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

### Quality Time (Child)

**2.82**

Families feel CCF supports them in spending quality time with their child/children.



## In Families' Own Words: The Greatest Support from CCF

Qualitative feedback was collected across all CCF families currently with 73% of providing feedback on what they felt was the most helpful information provided by CCF.

In general, families feel that the general support from CCF, knowing they are there and available, has been the greatest support. Themes that emerged from the feedback of families, is that the greatest support from CCF has been the education they provide (both in regard to the cancer journey, support services available, and how to communicate with their family and community), as well as providing financial assistance, such as food and petrol support, providing counselling services, and the Beads of Courage program.

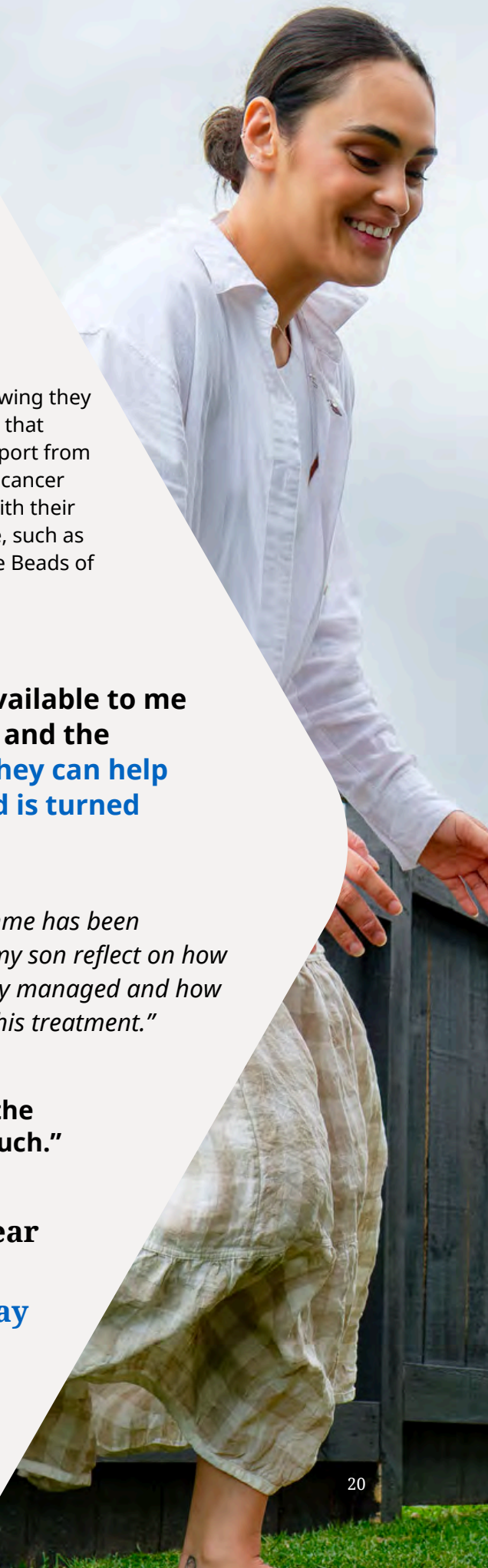
**“Our family support worker is lovely, approachable, friendly. We love her visits, and my son loves getting his beads. She helped us organise counselling. She is a lovely, constant support for us.”**

**“The supports available to me and my whānau and the different ways they can help when your world is turned upside down.”**

*“The beads programme has been amazing. It helped my son reflect on how much he had already managed and how far we had come in his treatment.”*

**“The short term financial help and being given the grant for personal development helped us so much.”**

**“Just being a really friendly, supportive ear and providing support such as petrol vouchers and groceries to make day to day life a little easier.”**





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

CCF is currently operating under a three-year strategic plan for 2022-2025, guided by four key pillars aimed at enhancing its overall impact on the families it serves and the broader pediatric cancer support community.

The four pillars are:

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

The following sections examine CCF's progress against key performance metrics and provide insights into areas that may lead to 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 2023-2024 reporting period. To understand the impact of quality service delivery across all aspects of the organisation, the following outcomes metrics were 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?



# 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

**76.8% of families surveyed reported having access to all the support services they need,** which is a 4.8% increase from the previous year. This coincides with 91.78% of families reporting that CCF has assisted them with accessing services. Further, the higher the attribution to CCF, the greater families felt they could access the services.

Across all of CCF services provided, families feel most supported in accessing FSC's, short-term financial support, Whānau Connect Groups, and holiday homes. They feel least supported in accessing the respite services.

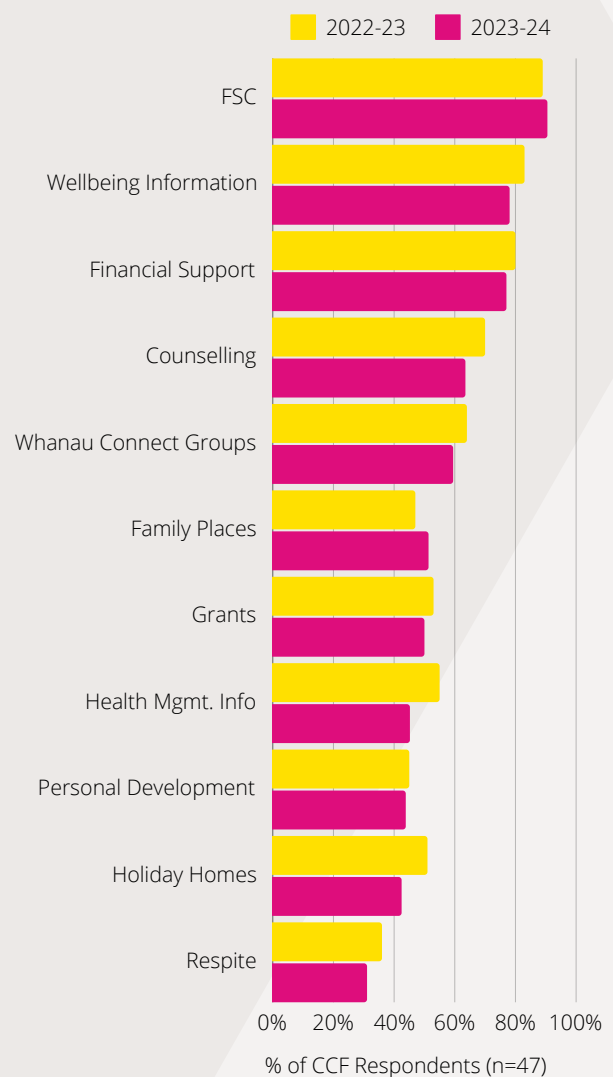
## CCF Service Use

There is a common trend across last year and this year as the the most and least utilised CCF Services. Similar to last year, **CCF families most often utilised FSCs, wellbeing information, and short-term financial support.** They further reported least utilising the respite services. This coincides with feeling least supported in accessing respite service. This suggests an opportunity for CCF to help families access respite, which could increase its use.

In relation to bereaved families, **60% of families surveyed reported using bereavement support services offered by CCF,** and that these services are at least somewhat meeting their needs.

**94%** of families who responded in 23-24 have engaged with CCF in the past six months or less

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





# CCF Families' Access to Counselling Services

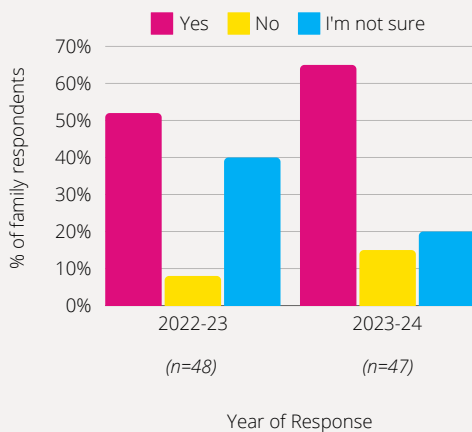
Caring for a child with cancer impacts many aspects of family life, with families facing complex issues throughout the journey that can cause significant psychological distress. Counselling services can help families to decrease stress, cope with setbacks and manage their emotions during this challenging time, providing benefits not only to caregivers but to the child with a cancer diagnosis as well.<sup>6</sup>

This year there was a decrease in use of counselling services, with 29% of respondents accessing counselling, compared to 70% in 2022-23. Despite a smaller proportion of families accessing counselling, 71.43% of these families say that these services met their needs at least somewhat to completely, a similar result to 75% in 2022-23. This indicates that counselling continues to be a valuable and important resource for families who engage with these services.

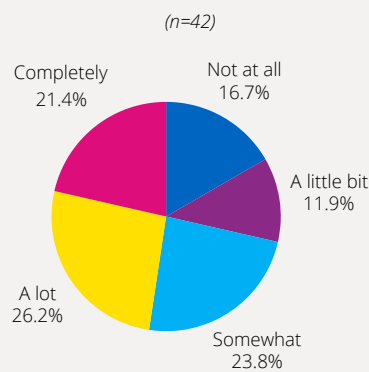
**Of those who have engaged with counselling, 81% report that CCF has helped them to access these services, highlighting the crucial role that CCF plays in helping families access the support they need.**

In 2023-24, 65% of respondents were offered counselling by CCF. This is an improvement from last year which saw 52% of families offered counselling. However, of those who were not offered or were unsure, only 35% reported knowing how to access services, compared to 75% in 2022-23 who knew how to access counselling despite not being offered the service.

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



**How Well Counselling Services Met Families' Needs in 2023-24**



These results suggest that there is opportunity to offer counselling to more families who could benefit from this support, but may face barriers to accessing these services independently. Continuing to offer this service more widely can help to ensure that families can readily access this support should they need it.





# 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, more than half of CCF families (58%) reported feeling satisfied with their current state of holistic wellness, which is a +15% increase from last year's measurement.<sup>^</sup>**

Compared to last year, more families have higher frequencies of feelings anxious and angry, are feeling more helpless at times, and have less time to look after themselves. However, more families feel they have the opportunity to maintain their physical wellness, have had moments of joy, and have things to hope for.

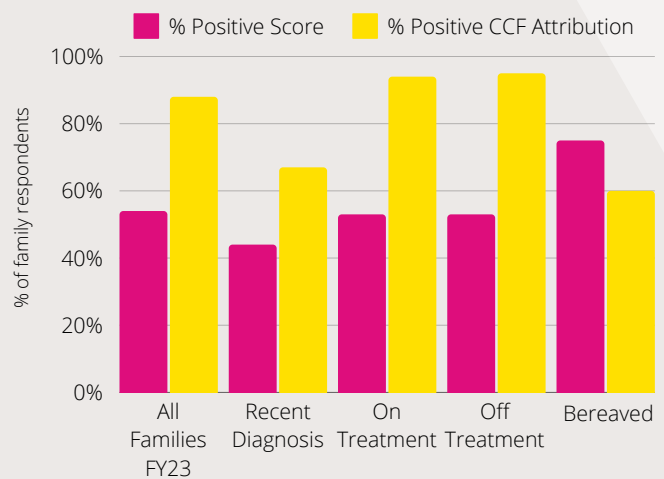
On average, 63% of families report feeling at least a little bit to completely supported across all holistic wellness factors. Families attributed the greatest CCF support to feelings of hope and experiencing moments of joy, and the least support in feelings of anger and having the opportunity to maintain their physical wellness.

Results suggest across all factors, that families feel less supported by CCF in managing their holistic wellness, compared to last year. This may be reflective of families in general having greater overall holistic wellness and needing less support.

<sup>^</sup>Findings are not statistically significant ( $p > .01$ ), however they indicate a trend.

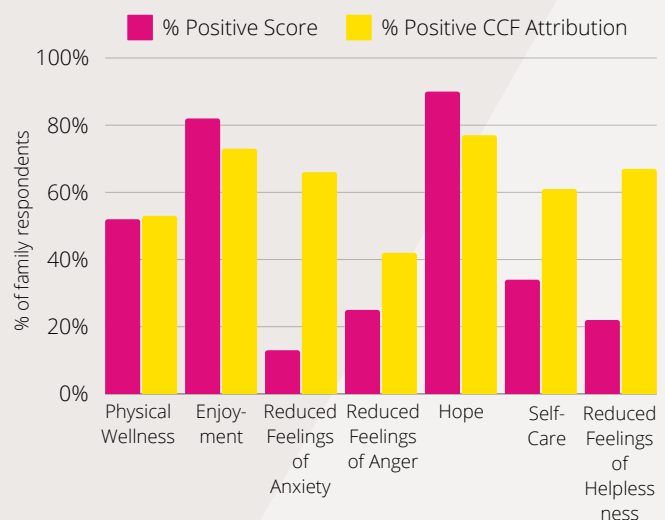
**58%** of families who responded in FY23 have positive feelings about their current wellness state

**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**





# 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.** This finding is a 2% reduction from last year's families.^ While there were no significant differences found in resilience across families, off-treatment families attributed the greatest support of resilience to CCF (95%).

Initial results suggest that 100% of bereaved families are feeling positive about their resilience. This is a 65% increase from last year.^ This year's finding is seen with 80% of bereaved families attributing their resilience to the support of CCF. Further, 100% of bereaved families feel they can adapt when unexpected events happen.

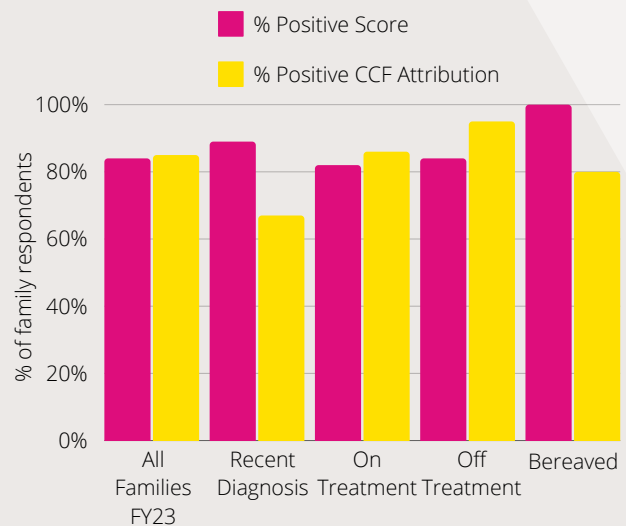
Similar to last year, across all resilience factors the majority of families report feeling at least slightly satisfied with their personal capabilities and 86% of all families feel that CCF has supported them with these capabilities at least a little bit. Unsurprisingly, four out of five families report 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.

What has helped families remain resilient in their own words will be explored on the next page.

<sup>^</sup>Findings are not statistically significant ( $p > .01$ ), however they indicate a trend.

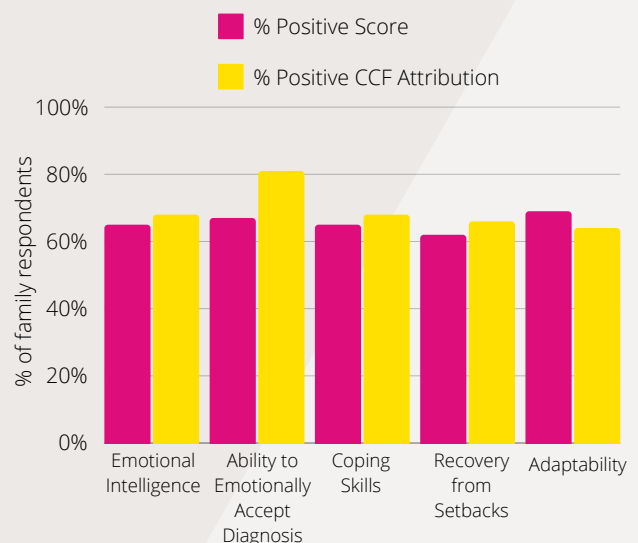
**66%** of families who responded in FY23 feel at least slightly satisfied with their personal resilience

**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**





## In Families' Own Words: What Has Helped Families Remain Resilient

Families were asked to reflect on what has helped them remain resilient. The strongest themes that emerged centred around interpersonal relationships and having a supportive family and friend network. The next greatest source of support in feeling resilient was a sense of faith, followed by having a supportive community and whānau.

**“The support of my whānau and close friends. Gifts of koha in any and every form. Taking moments to be present with each of my children individually, my husband, myself and all of us together.”**

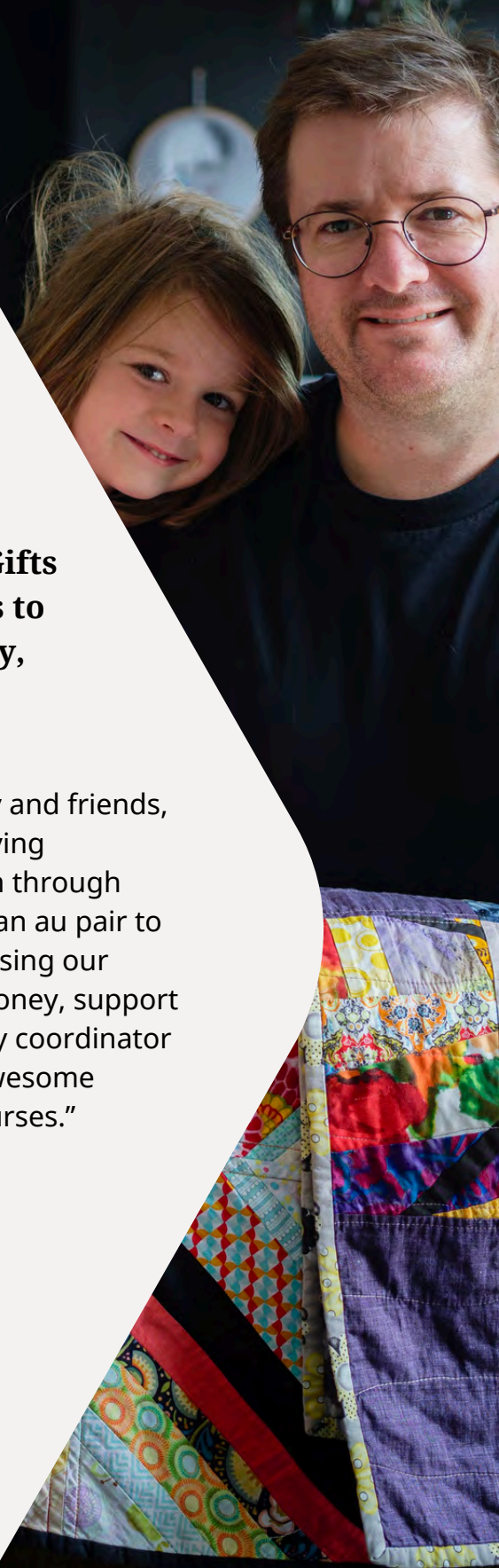
*“Family and friend support, the staff on the ward and our Child Cancer Foundation support worker who always rings and texts.”*

**“Having friends that did little things when we needed the most. Our Christian faith and our very strong and amazing family of 5. Together we are winning this battle.”**

“Support from family and friends, meals delivered, staying connected with them through social media. Hiring an au pair to help with childcare using our trauma insurance money, support from [our] CCF family coordinator and True Colours, awesome Waikato oncology nurses.”

**“The support I have received from family and friends.”**

The impact of establishing strong relationships will be explored next in this report under Theme 2: Powerful Relationships.





## Theme 2: Powerful Partnerships

The following section examines how CCF has worked towards achieving Theme 2 for the 2023-2024 reporting period. To understand the impact of creating and maintaining powerful partnerships for families, the following outcomes metrics will be assessed:

- **Connection to Others:** Where do families connect with their community and support networks?
- **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 Are Made

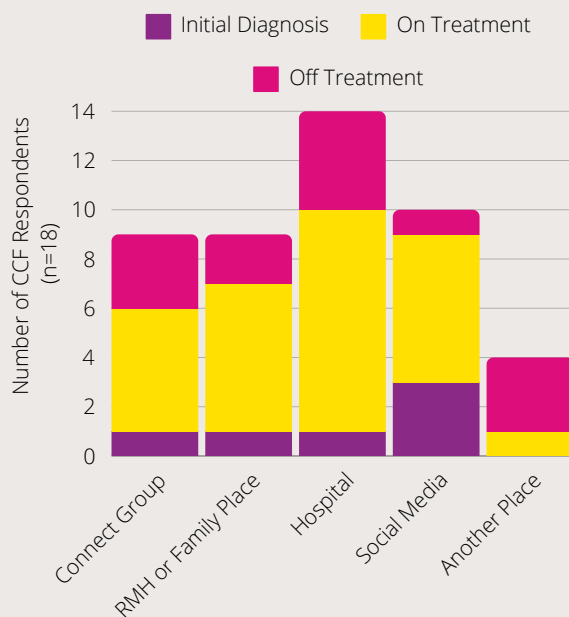
When completing the 2022-23 Wellbeing Survey, about one quarter of families (24%) indicated where they're connecting with others. **Majority of families who responded indicated that they connected with other families at the hospital where their children were receiving treatment (44%) and also online through social media groups (28%) and at a Connect Group event (28%).** 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 and in connect groups, as well as through online support networks.

## Personal Relationships

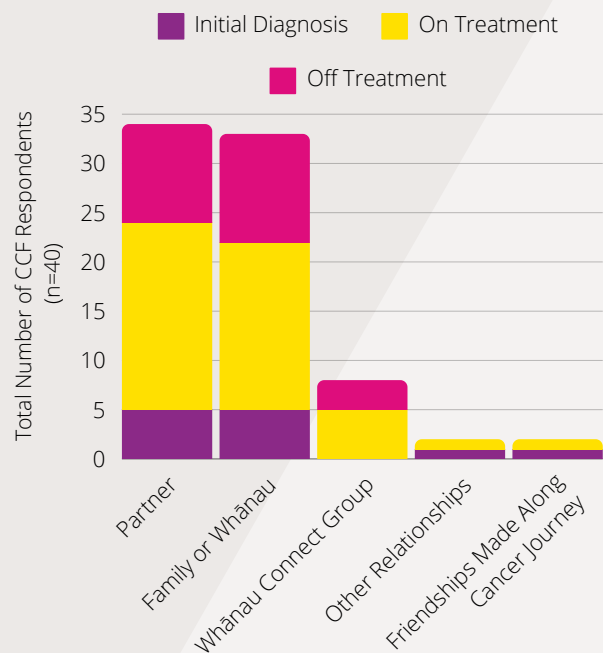
In addition to connections facilitated by CCF, the Wellbeing Survey asked families about their supportive personal relationships. Just over half of families (54%) reported on which people and relationships in their life understand how they feels. Of those who responded: 55% reported that the feeling understood by their partner, and 58% by their family or whānau.

The next greatest source of supportive relationships were seen from friendships created since their child's cancer diagnosis (22%), and friendships created through their local Whānau Connect Group (10%).

Places Where CCF Families Connect, 2022-23



Supportive Personal Relationships, 2022-23





**"CCF has given me an incredible support network. I would have been completely lost [without my Family Support Coordinator] and my whānau connect group. CCF is such an incredible organisation."**

- 'CCF Wellbeing Survey' Respondent  
Not pictured

(Family member responded when their child is in On Treatment stage)



# 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, over two-thirds of CCF families reported feeling positive about the relationships they have in their lives.** This is a 6% increase from last year.<sup>^</sup> This was highest among bereaved families, as 100% reported feeling at least slightly satisfied with their relationships. Further, 100% of bereaved families feel they have people in their life who help and support them, and that the people in their life understand how they feel.

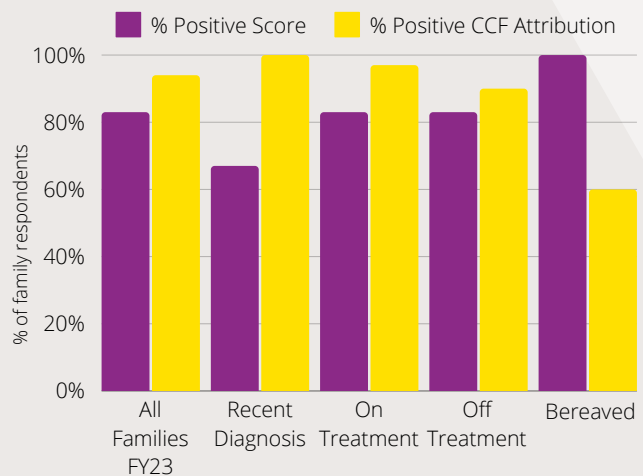
**Recently referred families reported the greatest attribution to CCF for supporting them with their personal relationships.** This coincides with recently referred families also feeling the least satisfied in this area. These findings demonstrate how CCF is focusing their resources to support families at the beginning of their journey where it is most needed.

In terms of individual factors, families reporting more support from CCF felt they were able to spend more quality time with their partners and people in their support network. Families further feel the most supported and score highest in their ability to spend quality time with their support network. However, **similar to last year, healthy partner relationships appear to be struggling the most**, with less than 40% of families feeling that they have enough quality time with their partner. Partner relationships was also identified as a priority need across the CCF community and will be explored greater on the following page.

<sup>^</sup>Findings are not statistically significant ( $p > .01$ ), however they indicate a trend.

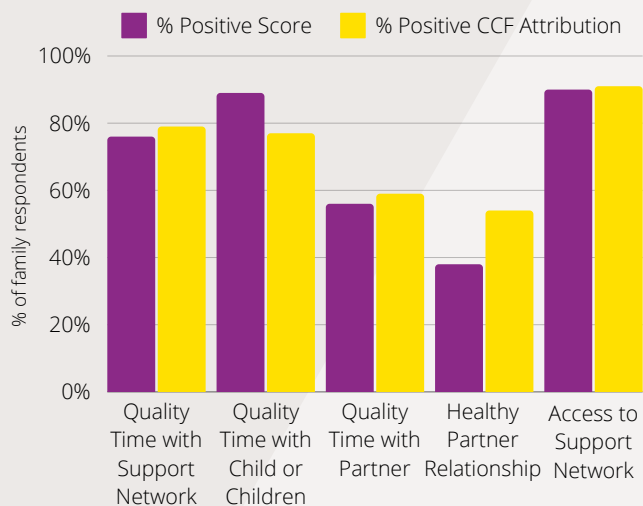
**71%** of families who responded in FY23 are at least slightly satisfied with their personal relationships

### 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



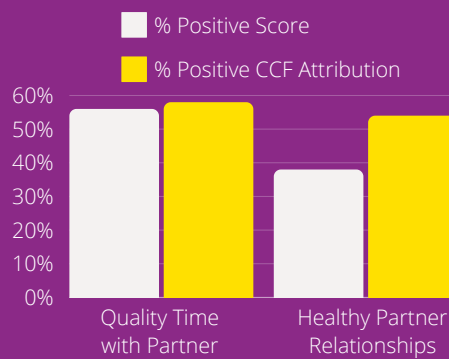


# Opportunities for Improving Impact: **Partner Relationships**

As mentioned earlier, **positive relationships between parents of a child with cancer is important**, providing essential emotional support, improving coping mechanisms, and positively influencing family well-being. Strong partner relationships help manage stress and emotional burdens, significantly reducing parental psychological distress.<sup>7</sup>

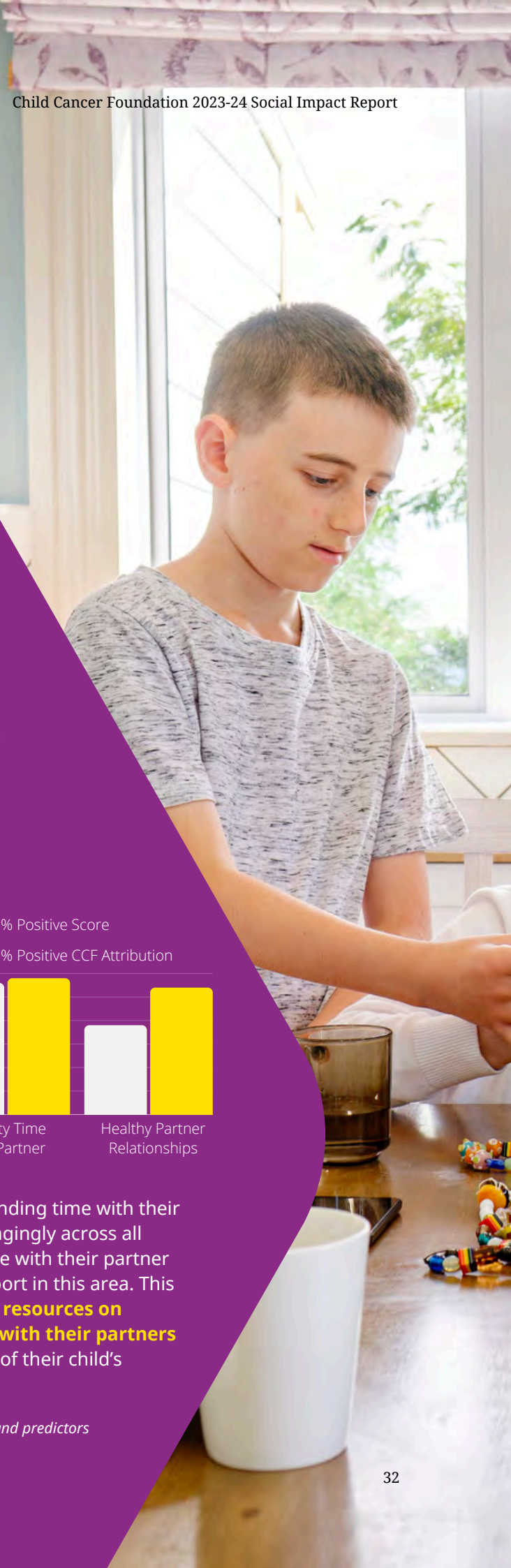
**Effective communication and support within the relationship further lead to better coping strategies and more consistent parenting**, which are vital for the child's emotional well-being.<sup>8</sup> Supportive relationships also result in fewer psychological symptoms, such as depression and anxiety, and act as a buffer against isolation, enhancing parents' resilience and quality of life.<sup>9-10</sup>

Our research shows that across all families, **parents/guardians who feel they spend more quality time with their partner have a greater ability to emotionally accept their child's cancer diagnosis**. Analysis further showed that spending quality time with one's partner was a priority need across all families. That is, it is a predictor of wellbeing and is scoring relatively low across the CCF community (4.53 scale of 1-7) .\*



It is understandable that families may not prioritise spending time with their partner during this time in their lives. However, encouragingly across all families, those who reported spending more quality time with their partner also gave a greater attribution to CCF for receiving support in this area. This demonstrates that **CCF should continue to focus their resources on promoting parents/guardians to spend quality time with their partners** to promote wellbeing and potential greater acceptance of their child's cancer diagnosis.

*\*For more information on correlation of CCF attributions to their factors and predictors of wellbeing, see the report appendix.*







# 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.**

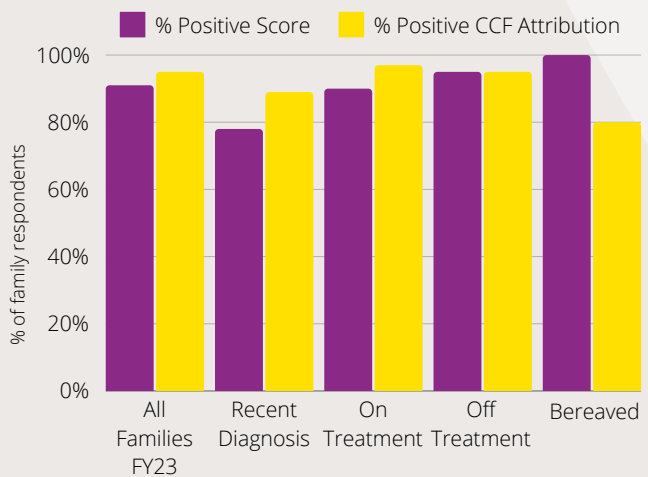
This year saw a 2% average increase in community connections compared to last year.<sup>^</sup> This is seen with the average family across all cancer stages feeling at least somewhat connected to their community. Individually, bereaved families scored the highest in community connection, with 100% of families scoring positively in this area. Further, 100% of bereaved families reported having people in their life who help and support them.

**This year, two-thirds of families felt connected to a community, which is an improvement from last year, whereby only half of families felt that they were connected.** However, the greatest difficulty was seen with less than half of families feeling that they could connect with other caregivers in a similar situation. This is seen with families reporting the least CCF support in this area. However, families who felt more supported by CCF in this area, also scored higher. This demonstrates the impact CCF support has in this area and provides an opportunity for CCF to continue to support families to connect with each other. The greatest CCF support was seen in assisting families to access support services. Further, it should be celebrated that 94% of families reported feeling treated with respect by their child's FSC.

<sup>^</sup>Findings are not statistically significant ( $p > .01$ ), however they indicate a trend.

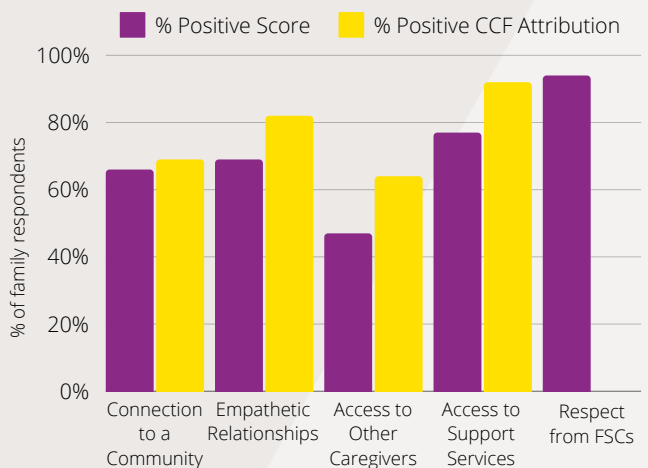
**71%** of families who responded in FY23 are satisfied with their community access and connection

**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*



*"[CCF has] helped me tremendously with my journey... **I feel like I have someone to talk to, who listens to me and understands me.**"*

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

*"Our support worker is a **positive relationship we have developed in this journey.** She is a friendly face and a listening ear."*

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





## Theme 4: Developing our Assets

The following section examines how CCF has worked towards achieving Theme 4 for the 2023-2024 reporting period. To understand the impact of developing and maintaining CCF infrastructure to support families, the following outcomes metrics were assessed:

- **CCF families' access to holiday homes, temporary accommodation and short-term financial support:** Which CCF resources have you used? 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

In 2023-24, there was a similar level of engagement with the tangible resources and assets offered by CCF when compared with last year. This indicates that financial support, access to holiday homes and temporary accommodation have continued to be valuable resources for CCF families. Consistent with last year’s findings, financial support remains particularly important for families in 2024.

## Short-term Financial Support

Families reported that short-term financial support is one of the most important services they receive from CCF. In 2023-24, 77% of survey participants used this service, with 98% of families reporting that CCF has helped them access this support.

Interestingly, families who had enough income to cover the cost of their everyday needs also felt that they had the skills to understand and manage their financial situation ( $r=0.814, p<.001$ ). Financial management often becomes difficult for a family, particularly if they have to stop working to support their child, while still covering costs such as daily needs and a mortgage. This presents **an opportunity**

**for CCF to assist families in providing education around finances and financial management,** empowering families with the tools and knowledge they need to navigate their changed financial circumstances more effectively.

There is a high correlation between families who are able to access the support services they need (including but not limited to health care, financial, education, employment, healthy homes and spiritual services), and also having enough income to cover the costs of their everyday needs ( $r=0.706, p<.001$ ). 91.78% of families reported that CCF has helped them access the support services they need. This highlights the **success and continued importance of CCF in developing their resources to assist families who may not be able to access the support services they need due to restrictions in their income.**

## In Families' Own Words

"Living costs **relief with petrol costs and food costs** we appreciated a lot."

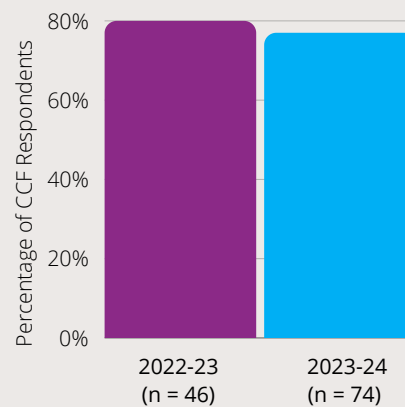
"Financial support from CCF has been a huge help as it's **taken away a lot of stress.**"

"[Our support coordinator] accessed us food... she has applied for grants for my children to attend sports... she has given us petrol vouchers... **we are nothing but grateful to CCF.** Thank you all so much."

"They **provided much needed support.** Grocery shopping was the most value to us as we had to give up work and still pay a mortgage."

"The food cards/purchase cards were of **immense relief.**"

Use of Short-term Financial Support, by Year





# Supporting Families with Tangible Resources

## Temporary Accommodation

At the time of completing the survey, 57.58% of respondents reported that they had been living away from their usual whānau and/or support network in the past week in order to receive treatment. 41% of these families reported that CCF has helped them access temporary accommodation.

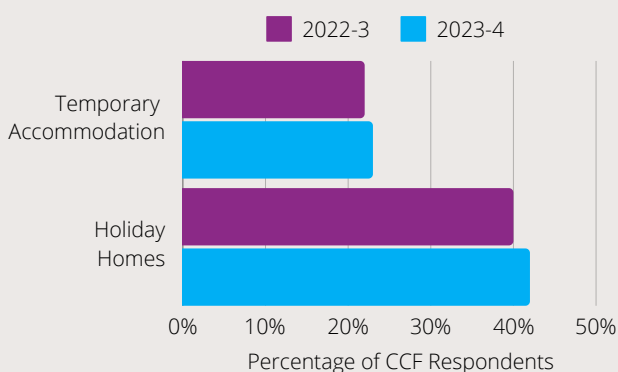
Generally, families who accessed this service reported that the quality of hospital meals, toiletries and entertainment were from average to high quality. 100% of these families reported having access to the right technology to stay in touch with family and friends.

## Holiday Homes

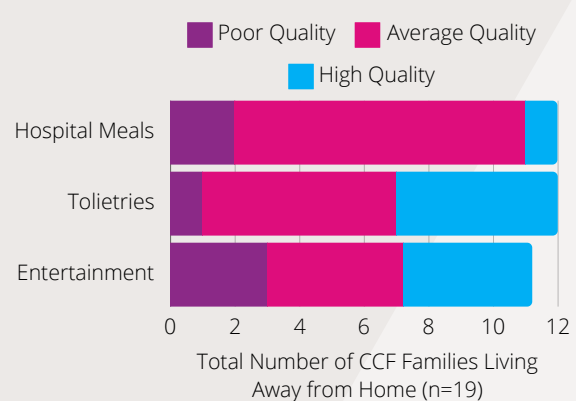
In 2023-24, 42% of survey respondents said that they had accessed holiday homes. 74% of these families reported that CCF helped them access this service, highlighting the important role that CCF plays in providing this resource.

Qualitative feedback from families indicates that those who used holiday homes found this to be very beneficial. Some qualitative responses reported difficulties with accessing this resource, suggesting that there may be an opportunity to support more families who wish to utilise this service.

Use of Temporary Accommodation and Holiday Homes, by Year



Quality of Resources When Living Away from Home



## In Families' Own Words

"We used the Arrowtown holiday home recently and this was **so beneficial to us as a family after the last year.**"

"Easier access to a holiday home and easier contact to try and arrange this would have made a huge difference for our family."

"The greatest support was the use of the Taupō holiday home to get our daughter away for **a much needed break.**"

A list of the main services provided and how families engaged with these over the past year can be found on page 24.



## 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 in various other publications.

The following pages offer data-driven insights to guide Family Support Coordinators in their daily support of families. Each page presents an overview of families' strengths, challenges, priority needs, and the areas where they feel most supported by CCF at various stages of a child's cancer journey in 2023-24. These stages include recently referred; on treatment; off treatment; and those experiencing bereavement.

### Similarities and Differences Across All Stages

There are shared trends from family responses across all stages:

- All CCF families **feel CCF support them greatly in accessing the support services they need.**
- Recently referred, on-treatment and off-treatment families **feel respected by Family Support Coordinators.**
- Both recently referred and on-treatment families **feel they get to spend quality time with their child.**
- Both recently referred and on-treatment families **share the same priority need of self-care.**
- The **greatest challenges** across all stages center around the **experience of negative feelings.**





# Child Cancer Foundation Families Recently Referred

## Average Wellbeing

# 5.57

Scale of 1-7

n = 9

Families who have been recently referred to CCF are reporting the highest overall wellbeing score of 5.57 which represents a trend to improve from 2022-23 which saw an average wellbeing score of 4.65. 100% of families at this stage report CCF is supporting them in having enough income for their everyday needs. Families also feel strongly supported in having access to services and having people in their lives who help and support them. Priority needs at this stage are self-care and addressing families' feelings of helplessness.

## 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

# 6.67

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

### Hope and Optimism for the Future

# 6.50

Families strongly feel they have things to hope for.

### Relationship with Child (Quality Time)

# 6.33

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:

### Relationship with Partner (Coping with Pressures)

# 5.33

Families report struggling in their partner relationships due to pressures from their child's cancer diagnosis.

### Mental Health - Anxiety

# 5.88

Families report recent feelings of anxiousness.

### Feeling Helpless

# 6.00

Families report feeling helpless.

## Priority Needs

Supporting families by providing opportunities and building capabilities to reduce their sense of helplessness and increase self-care are areas to prioritise. These areas have the strongest relationship with wellbeing for families at this stage.



## CCF Strengths

Families are feeling most supported by CCF in having enough income to cover the costs of their everyday needs, being able to access the support services they need, and having people in their lives who help and support them.



# Child Cancer Foundation Families On Treatment

## Average Wellbeing

# 4.85

Scale of 1-7

n = 37

Families are reporting their lowest wellbeing score of 4.85 at this stage as they experience the challenges of caring for their child during cancer treatment. This represents a trend of decline compared to last year which saw a wellbeing score of 5.18. Lack of time and energy for self-care is one of the main challenges identified, and is an area to prioritise for families' wellbeing. Consistent with families who have been recently referred, families in the on-treatment stage are reporting that CCF is strongly assisting in facilitating their access to services and providing supportive relationships.

## 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

## 6.68

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

### Relationship with Child (Quality Time)

## 6.31

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

### Daily Life Skills (Parenting)

## 6.19

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

## Challenges Faced

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

### Self-Care

## 3.59

Families report not having enough time and energy to look after themselves.

### Feeling Helpless

## 4.80

Families report feeling helpless.

### Mental Health - Anxiety

## 5.45

Families report recent feelings of anxiousness.

## Priority Need

Similar to the recently referred stage, self-care is also a priority need for families in the on-treatment stage. This area is the lowest scoring factor, and has the strongest relationship with wellbeing for families at this stage.



## CCF Strengths

Families report that CCF has most assisted in being able to access support services they need, and having people in their lives who support them and understand how they feel.





# Child Cancer Foundation Families Off Treatment

## Average Wellbeing

# 5.41

Scale of 1-7

n = 21

Families report a higher wellbeing score of 5.41 when their child is off treatment, compared to the on-treatment stage. This represents a trend to improve from last year which saw a wellbeing score of 5.22. Priority needs for families at this stage are being able to spend quality time with their partner, and to strengthen their ability to handle many things at once. Families are feeling most supported by CCF in having supportive relationships, which has also been a continued strength throughout the first two stages of the cancer journey.

## 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

# 6.62

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

### Relationship with Child (Quality Time)

# 6.17

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

### Daily Life Skills (Parenting)

# 6.11

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

## Challenges Faced

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

### Relationship with Partner (Coping with Pressures)

# 4.30

Families report struggling in their partner relationships due to pressures from their child's cancer diagnosis.

### Feeling Helpless

# 4.89

Families report feeling helpless.

### Mental Health - Anxiety

# 5.11

Families report recent feelings of anxiousness.

## Priority Needs

Areas to prioritise for families during the off-treatment stage are being able to spend quality time with their partner, and strengthening their ability to handle many things at once. These areas have the strongest relationship with wellbeing at this stage.

Improvement in these areas is predictive of increased wellbeing for families while their child is off treatment.

Handling Many Things at Once

Quality Time With Partner

## CCF Strength

Similar to last year, at this stage, families are feeling most supported by CCF in having people in their life who help and support them.



# Child Cancer Foundation Families Experiencing Bereavement

## Average Wellbeing

# 4.94

Scale of 1-7

n = 5

This year's findings represent a trend for an increased overall wellbeing score compared to last year's score of 3.92 for families experiencing bereavement. ^ 100% of families at this stage report that they can adapt when unexpected events happen, and that they have supportive people in their lives who understand how they feel. Families are feeling most supported by CCF in the areas of information of grief and support services, community connection and facilitating quality time in relationships.

## Participant Strengths

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

### Strong Family Unit

# 6.67

Families feel their family looks out for each other.

### Supportive Relationships

# 6.67

Families feel they have people who help and support them.

### Daily Life Skills (Household)

# 6.50

Families report being able to do what is necessary to run the household.

### Adaptability

# 6.50

Families report being able to adapt when unexpected events happen.

## Challenges Faced

Low scores across the following three factors indicate that families are experiencing obstacles and challenge most associated with feelings of negative emotions:

### Mental Health - Anger

# 5.50

Families report recent feelings of anger.

### Mental Health - Anxiety

# 4.75

Families report recent feelings of anxiousness.

### Loneliness

# 4.75

Families report feelings of loneliness.

## CCF Strengths at this Stage

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

### Information Network Support

CCF has helped families gain knowledge of grief and bereavement support services.

### Facilitating Quality Time in Relationships

CCF has helped families to spend quality time with the people they care about.

### Community Connection

CCF has helped families to connect with people in their lives who understand how they feel. Families also report CCF has helped them to have the opportunity to talk to other caregivers who have lost a child to cancer.

^Data collected is from 21% of all families engaged with CCF who have lost a child from cancer in the last 18 months. The low sample size of five families 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 limited in our understanding of the shifts in wellbeing and outcomes that occur for families who progress to this stage.



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

Across all CCF families from recently referred to bereaved families, there was consistent gratitude and appreciation for the incomparable support that CCF offers in relation to their calls, messages and visits, and just by having someone there to call upon when needed.

The second most mentioned impact on their lives was the financial support that CCF provides, whether it be in the form of short-term financial assistance, groceries and petrol support, or entertainment support. 67% of families report CCF assisting them with having enough income to cover the cost of their everyday needs.

**“We are so lucky to have such amazing people who care for others. I don't know how I would have handled a lot of things without the help I received.”**

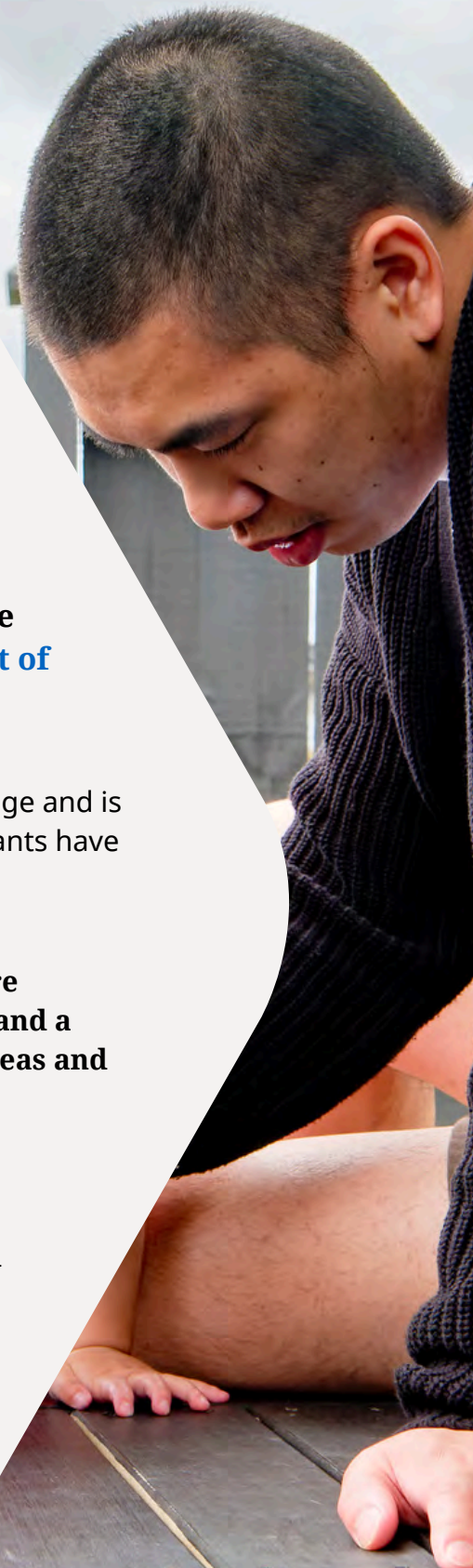
“Having a connection with someone who cares and has knowledge and is supportive has been amazing. The generous food and petrol grants have been a **huge stress relief** as a single mum.”

*“They have been **a constant in our lives** since almost day one of our son's diagnosis. It is refreshing to have a nice caring person at the end of the phone or to help us out when we are in at the hospital. It certainly has made the journey somewhat more manageable knowing there is that one person to ask if we need anything.”*

**“They have been there through the journey and a great support with ideas and coping strategies.”**

**“It's like **a safety net**, there to catch me if I wobble or fall.”**

**“The support from our family coordinator has been greatly appreciated. It has greatly assisted with a lot of financial burden during this stressful time. And **it's been a relief knowing there's someone to turn to.**”**





*"Thank you for all you have done for us.  
**We appreciate the support during this  
difficult time!**"*

*- 'CCF Wellbeing Survey' Respondent  
(Family member responded when their child is in Recently Referred stage)*

*"Keep up the great work. **You are making  
a positive difference.**"*

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

*"Keep doing what you are doing, your  
service is amazing and **our families are  
so lucky to have your support** when  
going through a child cancer diagnosis."*

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





# Get in Touch



## Child Cancer Foundation

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## Appendices:

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



# 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 ensure the integrity of findings, Huber Social includes a Transparency Page for every project. This ensures both the rigour of evidence and rigour of analysis is clear for each project, across every stage of the data lifecycle.



Phase	Questions on the Treatment of the Data		Points Allocated	Yes or No
<b>Design</b>	ACCESSIBILITY	Elements of the project (tools, methods, etc.) have been designed and tested to be accessible for all eligible study participants in the given population	1	Yes
	INCLUSION	Details of people specifically included (or excluded) in the measurement: <i>Insert description</i>	N/A	N/A
<b>Data Collection</b>	SURVEY DISTRIBUTION	Online surveys		Yes
		OR hard copy surveys		
		Data collection supervised by Huber Social consultant	1	No
		Translations or guidance provided		Yes
		Details on translation or guidance if provided: <i>Insert if required</i>	N/A	N/A
SAMPLE	Sample size has achieved 80% statistical power with a medium effect size of Cohen's $d = 0.5$ (t-test) or $d = 0.25$ (ANOVA)	1	No	
<b>Data Cleaning</b>	CLEANING	Partial responses removed or no partial responses	1	Yes
		Details of any responses removed: <i>Insert details</i>	N/A	N/A
<b>Analysis</b>	TEST APPLIED	Basic analysis	1	Yes
		Statistical Correlation Test	2	Yes
		Details on statistical analysis: <i>Insert details if required</i>	N/A	N/A
	STATISTICAL SIGNIFICANCE	Statistical significance cut off at $p < 0.1$ for all findings presented	1	Yes
OR Statistical significance cut off at $p < 0.05$ for all findings presented		2		
<b>Reporting</b>	REFERENCING	Understanding findings in the context of prior research/literature (either HS or external)	1	Yes
		Details on external sources referenced: <i>Insert details if required</i>	N/A	N/A
	DEVIATIONS	Details on any deviations from the original measurement approach, as delineated in the Measurement Plan, and their potential effect on data and findings:	N/A	N/A
	REPORTING	Client commits to sharing findings internal to the organisation	1	
		OR Client commits to sharing findings internally and with stakeholders external to the organisation	2	
OR Client commits to sharing findings internally, with stakeholders and the general public		3	Yes	
<b>RIGOUR SCORE: LOW (1-6); MED (7-10); HIGH (11-13)</b>			<b>MEDIUM</b>	<b>10</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 (Scale of 1-7)	Attribution Score (out of 5)	Correlation Coefficient	p-value
Enjoyment	CCF Community	5.85	2.6	0.501	< .001
Supportive personal relationships	CCF Community	6	3.32	0.483	< .001
Adaptability	CCF Community	5.15	2.4	0.442	< .001
Hope	CCF Community	6	2.8	0.435	< .001
Quality time with partner	CCF Community	4.53	2.19	0.41	0.004
Emotional intelligence	CCF Community	4.91	2.44	0.405	0.001
Helplessness	Recently Referred	6	1.5	0.947	0.004
Hope	Recently Referred	6.5	2.44	0.922	0.001
Self-Care	Recently Referred	4.38	1.67	0.712	0.048
Supportive personal relationships	On-Treatment	6.17	2.89	0.607	<.001
Overall experience with CCF	On-Treatment	2.92		0.554	<.001
Quality time with child/children	On-Treatment	6.31	2.76	0.549	0.003
Respect by FSC	On-Treatment	6.68		0.541	<0.001
Enjoyment	On-Treatment	5.87	2.56	0.485	0.005
Self-care	On-Treatment	3.59	2.22	0.472	0.011
Access to support services needed	On-Treatment	5.59	3.46	0.44	0.022
Adaptability	On-Treatment	4.06	2.4	0.437	0.011
Coping	Off-Treatment	4.78	2.45	0.722	<.001
Quality time with partner	Off-Treatment	4.94	2.21	0.618	0.011
Enjoyment	Off-Treatment	5.58	2.8	0.57	0.009
Emotional intelligence	Off-Treatment	5.21	2.9	0.513	0.021
People who understand how I feel	Off-Treatment	4.95	2.67	0.483	0.036
Helplessness	Off-Treatment	4.81	2.28	-0.499	0.041



# Analysis Approach and Results

**Table 2. All Attribution Factors**

All factors significantly correlated with their CCF attribution score.

Factor	Stage	Average Score (Scale of 1-7)	Attribution Score (out of 5)	Correlation Coefficient	p-value
Access to support services needed	CCF Community	5.52	3.32	0.656	< .001
Opportunity to talk to other caregivers	CCF Community	4.47	2.4	0.501	< .001
Quality time with partner	CCF Community	4.53	2.19	0.424	0.002
Quality time with support network	CCF Community	5.29	5.17	0.406	0.002
Access to support services needed	Recently Referred	4.83	2.78	0.9	0.015
Access to support services needed	On-Treatment	5.59	3.46	0.81	< .001
Quality time with support network	On-Treatment	5.21	2.76	0.691	< .001
Opportunity to talk to other caregivers	On-Treatment	4.43	2.47	0.608	0.003
Quality time with partner	On-Treatment	4.48	2.17	0.58	0.002
People who understand how I feel	On-Treatment	5.32	2.92	0.57	0.002
Supportive personal relationships	On-Treatment	6.17	3.51	0.532	0.003
Opportunity to maintain physical wellness	On-Treatment	4.65	1.91	0.482	0.007
Ability to bounce-back	On-Treatment	4.91	2.49	0.43	0.014
Emotional intelligence	On-Treatment	4.62	2.31	0.406	0.019
Access to support services needed	Off-Treatment	5.47	3.24	0.583	0.007



# 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, and are only comparable to data from 2022-23 onwards.

## 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.



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