# Child Cancer Foundation Social Impact Report 2025

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

April 2024 – March 2025

Prepared by

HUBER SOCIAL

# Mā te whakarongo, ka mōhio, mā te mōhio, ka mārama, mā te mārama, ka matau, mā te matau, ka ora.

Through listening, comes knowledge, through knowledge, comes understanding, through understanding, comes wisdom, through wisdom, comes wellbeing.

……

Data used in this report was collected from across Aotearoa New Zealand with an approach and ethical considerations aligned to the principles and requirements of both the New Zealand National Ethical Standards and Te Ara Tika Guidelines for Māori Research Ethics.

With the majority of the Huber Social team residing in Australia, Huber Social continue to acknowledge, wherever their work takes them, the traditional owners and custodians of country throughout Australia. They acknowledge their continuing connection to land, waters, and community. They pay their respects to the people, the cultures, and the elders past, present and future. This report was prepared and written by Huber Social on the lands of the Bediagal clan of the Dharug people, who were also known as the Bidjigal people, and Guringai people of the Eora Nation, and the Whadjuk people from the Noongar Nation.

# Executive Summary

**This report provides the 2024-2025 overview of results of the social impact measurement of Child Cancer Foundation New Zealand (CCF), exploring the impact it has had on the families it supports, as well as identifying opportunities for improvement in the future.**

A childhood cancer diagnosis can completely upend the lives of a family. For over 45 years, CCF has been committed to ensuring no family faces childhood cancer alone. Beyond medical treatment, CCF understands the best way to support children with cancer is to provide wrap around support services to the whole family, helping with everything from financial stress and emotional wellbeing to everyday challenges and building a supportive community. Partnering with social impact measurement agency Huber Social since 2020, the social impact of CCF's programmes are measured in terms of wellbeing to ensure programmes contribute to genuine positive impact for the communities involved. Results inform internal decision-making, demonstrate to donors the impact of their contributions, and highlight opportunities for collaboration.

This Executive Summary provides a high-level view of this report. The **following section** of the report outlines the vision and mission of CCF, as well as CCF's theory of change, while **section three** covers the key insights arising from the social impact measurement. 2024-2025 measurement brought the voice of families to the forefront, with the aim of understanding what would help families most at each stage of the cancer journey, as well as families' strengths unique to them at that stage. Supplementing families' voices, **section four** lays out findings for CCF services and supports. Section five builds on findings from previous sections, examining what supports are most effective for families across the target outcomes. The report concludes with a discussion of Huber Social's methodology and approach to social impact measurement.

As CCF completes its fifth year of social impact measurement, a clear picture is formed of its positive impact on CCF families going through the cancer journey. The vast majority of families reported a positive experience with CCF, and credited CCF with helping them feel strong across target outcomes. Across stages, CCF Families had strong support networks, hope, and quality time and skills to care for their children, and were holistically supported by CCF across these strengths. Analysis for families going through different stages of the cancer journey revealed stage-specific strengths, as well as areas where support would help most for these families. These findings allow for a nuanced approach to better support families depending on which stage of the journey they are in, to best target impact. Additionally, the services and support CCF offered were generally found to be both accessible and helpful for CCF families. Positively, CCF fostered higher access for families across nearly every service compared to the last measurement period.

Looking to next steps, CCF has the opportunity to gain deeper insights and enhance support for families, leveraging five years of data and a strong, embedded measurement process. Continued improvements in measurement will continue to generate valuable insights, enabling CCF to further optimise its services to meet families' needs.

# Executive Summary

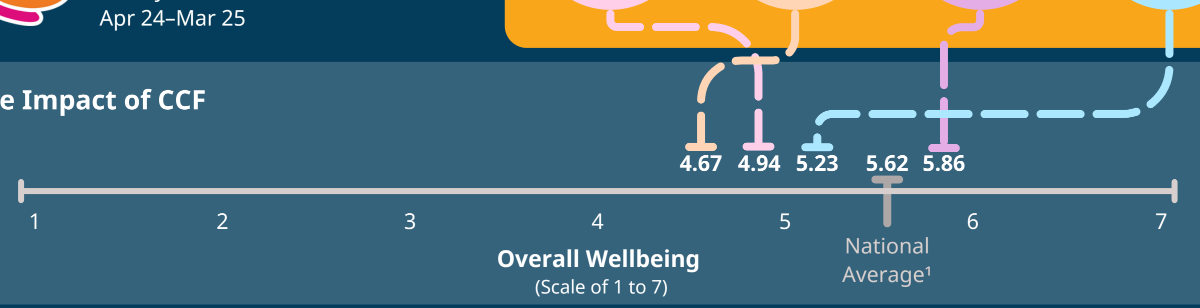
## Respondents

Families of children diagnosed with cancer, responding to CCF survey between Apr 24–Mar 25

CCF Survey Respondents (n=80; representing 21% of all CCF families)

- New Families (n=22)
- On-Treatment Families (n=30)
- Off-Treatment Families (n=21)
- Bereaved Families (n=7)

## The Impact of CCF



## Impact of CCF Across Families

**90%**
Reported a **positive overall experience with CCF**

**96%**
Agreed CCF helped them have **people in their life who help and support** them

**88%**
Agreed CCF helped them **access support services**

**85%**
Agreed CCF helped them have the skills to **care for a child with a cancer diagnosis**

## Impact of CCF Services

**Family Support Coordinators are at the heart of CCF's Impact**

95% Felt treated with respect by their Family Support Coordinator

**Families were Supported by Counselling Services Through CCF**

80% Felt the counselling services met their needs to at least some extent

**CCF Serves Families across Aotearoa, not just those in urban populations.**

**28%** of families responded that they lived in a rural area

## 2024-25 Recommendations

- **Further Emotional Support**
- **Further Support for Relationships / Connections**
- **Physical Wellness Support**
- **Accessing Counselling and Bereavement Services**
- **Maximising 5 years' of family voices**

### Most Helpful for New Families:

- Support around **strong partner relationships**
- Coping with feelings of **helplessness**
- Adaptability (support **to recover quickly after setbacks)**

### Most Helpful for On-treatment Families:

- Support around **emotional acceptance**
- Coping with feelings of **helplessness**
- Support to **maintain physical wellness**

### Most Helpful for Off-treatment Families:

- Support with **anxiety**
- Support around **late effects** after treatment

### Most Helpful for Bereaved Families:

- Support for feelings of **loneliness** and **anxiety**
- Further information on **bereavement support services**

# A Note from Child Cancer Foundation

## Nāku te rourou, nāu te rourou, ka ora ai te iwi.

With my [food] basket and your [food] basket, the people will live.

This year marks five years of collaboration between Huber Social and Child Cancer Foundation. During that time, we have collected a wealth of information and seen ongoing improvements in outcomes for whānau. The knowledge we have gained has enabled us to refine and tailor our support to each of the families we work with. Insights from the data collected have led to enhanced psychosocial support, better transition planning and improvements in how we respond to culturally, geographically and socioeconomically diverse families.

The information shared is extremely important to us; the data is critical in ensuring we continue to support families in ways that are relevant, meet their needs, and allow us to focus on what truly matters: the wellbeing of tamariki and whānau. The data has also helped us better understand the diverse experiences of whānau, including identifying disparities and tailoring support to better meet the needs of families for example, who come from more remote or rural communities, a cohort who have unique needs and challenges when accessing specialist paediatric oncology health services.

Our partnership with Huber Social enables us to collect this data through a trusted third party with deep expertise in wellbeing measurement. Working with an independent partner like Huber Social ensures the integrity and neutrality of the data collected, and their expertise has been instrumental in translating insights into meaningful action. The importance of capturing the 'voices' of families is paramount — it informs us, not only of how well we are doing, but also how we can respond effectively to contemporary families experiencing a childhood cancer diagnosis.

The process of data collection is not without its challenges however, as we are often engaging with people who are living through one of the most traumatic experiences of their lives. Despite this, the generosity of the whānau who share their experiences and perspectives with us is incredibly moving, and to them I extend a heartfelt thank you. This valuable taonga is something we value greatly. As we look ahead, we remain committed to deepening our understanding, evolving our services, and ensuring that every whānau continues to feel seen, supported, and valued.

Tēnā rawa atu koutou

**Monica Briggs**
MNZM, CEO Child Cancer Foundation

# About Child Cancer Foundation New Zealand

## The Need

Every year, roughly 150 children across Aotearoa New Zealand are diagnosed with cancer, turning that child and family's lives upside down.[3] In addition to the immediate medical attention required, families find themselves navigating a complex and emotionally, mentally and sometimes financially draining world of cancer treatment. CCF provides support to families so that they can continue to love and care for their child and themselves through times of turmoil.

## 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 hikoi mate pukupuku hei rangatu ngā whanake hēi awhi ngā tamariki i tēnei mate pukupuku.***

## How CCF Supports Families

### Family Support Coordinators

CCF ensures every newly diagnosed family has a dedicated Family Support Coordinator (FSC) who is there to provide specific support, every step of the way. FSCs provide an entry point for families to access CCF support to build further resilience, emotional wellbeing, social connection, practical support, and help them move forward.

### Building Resilience

Helping whānau maintain control of their lives, including opportunities for respite to ensure whànau can rest, re-energise, and maintain the strength to carry on.

### Social Connection

Maintaining integral connections for whānau through Whānau Connect Groups, opportunities for hospital visits, and holidays away to spend time with each other and create precious memories.

### Emotional Wellbeing

Providing day-to-day emotional support for whānau through CCF's *Beads of Courage* programme, which honours the child's strength and resilience throughout treatment.

### Practical Support

Lessening the financial impact of childhood cancer, including short-term financial support for unexpected costs.

### Moving Forward

Encouraging families to look to the future, navigating ongoing physical and emotional challenges, and supporting the loved ones of children who sadly don't survive.

# 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 of children facing cancer to be in the best position to successfully manage their cancer journey 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** | **Opportunities:** |
|---|---|
| Community connection | Relationships |
| Resilience | Social structures |
| Life skills | Resources |
| Holistic wellness | 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, participating in 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

"[CCF is] truly a foundation that **practices what they preach**."

*—CCF Wellbeing Survey Respondent*
*(From the Bereaved Families measurement group)*

"Child Cancer Foundation has been wonderful ... **I have felt so cared for** by Child Cancer Foundation."

*—CCF Wellbeing Survey Respondent*
*(From the Off-Treatment Families measurement group)*

"Through conversations with [our FSC] I have understood **there are people such as Child Cancer Foundation who genuinely care and are prepared to support families**. My family and I are so grateful for your support."

*—CCF Wellbeing Survey Respondent*
*(From the Off-Treatment Families measurement group)*

# Key Findings: CCF Families

The following section sets out the key findings of CCF’s 2024-2025 social impact measurement, covering:

- Key findings across CCF families
- Overall wellbeing findings
- New families
- On-treatment families
- Off-treatment families
- Bereaved families

# How CCF Supports the Strengths of its Families

This page sets out findings across all CCF families responding in 2024-2025 measurement. Key findings on specific measurement groups as well as the impacts of CCF's services, counselling, and tangible assets are detailed on the following pages.

## CCF Families had strong support networks, hope, and quality time and skills to care for their children

**86%**

Felt they had **people in their life who help** and support them and

**96%**

Agreed CCF helped them with this

**85%**

Felt they had things to **hope for**

**79%**

Felt they had the skills to **care for a child with a cancer diagnosis** and

**85%**

Agreed CCF helped them with this

**79%**

Felt they got to spend **quality time with their child/ren**

## Families were holistically supported by CCF in their above strengths, and in the following areas

**90%**

Reported a **positive overall experience with CCF**

**95%**

Felt they were **treated with respect** by their **Family Support Coordinator**

**88%**

Agreed CCF helped them **access support services**

**80%**

Agreed CCF helped them **emotionally accept their child's cancer diagnosis**

Families were particularly strong in their support networks, having hope, and in their care and quality time with their child/ren. The strengths of these families during difficult times shine through in these results. They also reflect the efficacy of CCF's support in these areas of strength, but also across other areas such as emotional acceptance, respect from FSCs, and access to support services.

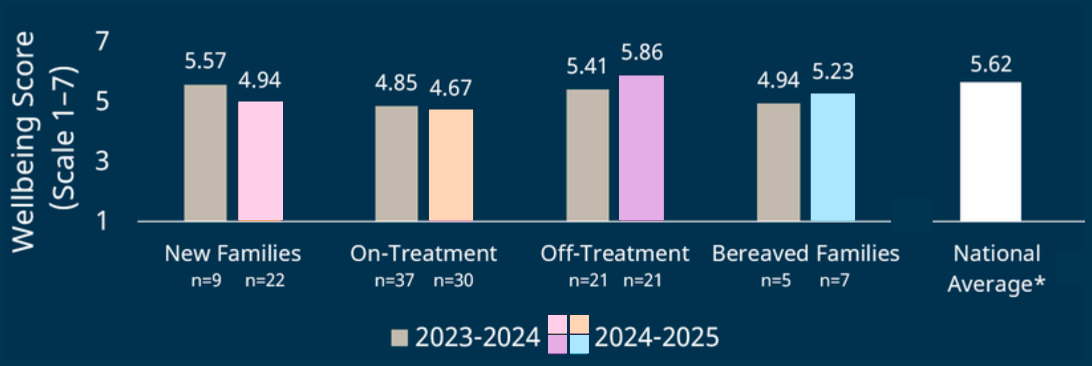
# The Impact of Child Cancer Foundation on Wellbeing

## Majority of CCF Families found some satisfaction with their lives

**80%** of respondents were at least somewhat satisfied with their lives

In 2024-2025 measurement, CCF families reported an overall wellbeing score of 5.09 (scale of 1-7), with 80% reporting they were at least somewhat satisfied with their lives. Although trending slightly lower compared to the previous measurement period (5.11), this score remains higher than the year before (4.82). In the wider context of what each family goes through during their child's cancer journey, the wellbeing of CCF families continues to present a good result.

## Wellbeing of CCF Families remained relatively stable compared to previous measurement



Within measurement groups, wellbeing saw a small downward trend for new families recently referred to CCF, and those on treatment. However, wellbeing scores trended positively for those off-treatment and bereaving families, suggesting families in these groups felt better about their lives during this measurement year. While these changes were not found to be statistically significant, they are indicative that CCF continues to deliver consistent support to families. The national average score provides a useful reference point for understanding how the wider Aotearoa New Zealand population is experiencing life. As the above graph indicates, on-treatment families are the only measurement group with a wellbeing score higher than the national average; all other measurement groups score below this reference.

**The national average satisfaction with life score and the scale used in this report are different; however, for the purpose of comparison, we have normalised them to the same scale. This score comes from the 2023 General Social Survey[1] and is based on a single question asking respondents "Where zero is 'completely dissatisfied', and ten is 'completely satisfied', how do you feel about your life as a whole?". This score was re-calculated onto 1-7 scale to correspond to wellbeing in this report, which is measured using the Satisfaction with Life Scale[2], with respondents rating their agreement with five statements on a scale from 'strongly disagree' to 'strongly agree'.*

# Strengths and What Helps Most for New Families

New families were those who had recently been referred to CCF within the last 3 months before taking the survey, and served as the “baseline” for CCF’s impact measurement (although CCF may have already started supporting them at point of measurement). Respondents in the new families category had a wellbeing score of 4.94, trending lower than the previous measurement period (5.57), indicating new referrals in 2024-2025 had joined with lower overall wellbeing compared to previous cohorts.

## New Families felt they had learnt ways to manage their emotions, and agreed CCF helped them manage feelings of anxiety.

95%

Agreed CCF has helped them have people in their life who **understand how they feel**.

89%

Agreed CCF helped them **manage the overwhelming amount of info** on their child’s diagnosis

89%

Agreed CCF has helped them manage feelings of **anxiety**

80%

Felt they have learnt ways to **manage their emotions**

## Support around strong partner relationships, coping with feelings of helplessness, and adaptability most helpful for New Families

1 in 4

Felt their **relationship with their partner was struggling** due to pressure from the cancer diagnosis (24%)

1 in 2

**Felt helpless** at times (50%)

1 in 4

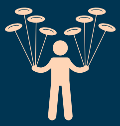
Didn’t agree that they tend to **recover quickly after setbacks** (27%)

Positively, new families showed strength in managing their emotions and having people around them who understand how they feel. The majority of new families also attributed their ability to manage feelings of anxiety and overwhelming amounts of information to CCF. New families had priority needs around partner relationships, coping with feelings of helplessness, and adaptability; support from CCF in these areas would be most helpful for these families.

# Strengths and What Helps Most for Families On Treatment

The on-treatment measurement group included families of children who were receiving cancer treatment at the time of measurement. On-treatment families reported a wellbeing score of 4.67, the lowest out of the current year's measurement groups and trending slightly lower than on-treatment families in 2023-2024 (4.85). This indicates on-treatment families may benefit most from the support of CCF to improve overall wellbeing.

## On-treatment families were strong in their resilience, management of their financial situation, and ability to process their emotions



**90%**
Felt they could **handle many things** at a time

**82%**
Agreed CCF helped them **manage the overwhelming amount of info** on their child's diagnosis

**82%**
Felt they could understand and **manage their financial situation**

**79%**
Felt they had learnt ways to **manage their emotions**

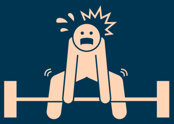
**3 in 5**
Felt their child's cancer treatment was progressing as planned

## Emotional and practical support is most helpful for on-treatment families

Based on data from the 2024–2025 measurement period, statistical analysis of on-treatment family responses did not identify priority needs (factors that are both statistically linked to wellbeing and are low-scoring). This may be due to high variation within the small sample size, which can reduce the clarity of statistical relationships and obscure clear priority needs. However, the factors below received the lowest agreement scores, indicating areas with potential for meaningful improvement.

**3 in 5**
Didn't agree they were able to **emotionally accept** their child's cancer diagnosis (59%)

**2 in 5**
**Felt helpless** at times (43%)



**3 in 5**
Didn't agree they had the opportunity to maintain their physical wellness (58%)

# Strengths and What Helps Most for Families Off Treatment

Those in the off-treatment measurement group were families of children who had previously been diagnosed with cancer, but had already undergone treatment and were in remission. Off-treatment families reported a wellbeing score of 5.86, which was the highest score out of measurement groups and above the wellbeing score for the same group in 2023-2024 (5.41). The high score of these families may be indicative of the fact that their child's cancer treatment was effective and their child was no longer requiring medical care for their diagnosis at time of measurement.

## Off-treatment families had recently felt joy, time to look after their physical wellness, and felt financially secure

**94%**
Recently felt they had **moments of joy**

**84%**
Felt they had the opportunity to maintain their **physical wellness**

**83%**
Felt they could understand and **manage their financial situation**

**79%**
Agreed CCF helped them **manage the overwhelming amount of info** on their child's diagnosis

## Support with anxiety and late effects most helpful for off-treatment families

**2 in 3**
Recently felt **anxious**
(65%)

**2 in 5**
Reported late effects
(43%)

As the families of children who were no longer being treated for cancer, it is unsurprising that off-treatment families reported the highest wellbeing scores across measurement groups. This was reflected in off-treatment families' strengths: feeling joy, having the opportunity to maintain their physical wellness and manage their financial situation, and have enough income. However, along with these strengths, the majority of families had recently felt anxious (65%), and 43% of off-treatment families reported late effects; problems caused by cancer treatment months or years after treatment (n=21). These included hearing loss, loss of an eye, nausea, tremors, fatigue, other physical challenges, mental health challenges, and weight challenges. Anxiety and late effects continue to be areas where further focus and support could greatly uplift families coming off treatment.

# Strengths and What Helps Most for Bereaved Families

Those in the bereaved families measurement group were families who sadly lost a child to cancer. The number of respondents for this group are generally smaller than other groups year on year, with seven respondents in this group during the 2024-2025 measurement period. These families had a wellbeing score of 5.23, slightly higher than the previous measurement period (4.94), and higher than the new families and on-treatment families measurement groups (4.94 and 4.67 respectively).

## Bereaved families reported being able to find moments of joy in life and spend quality time with loved ones

**100%**
Recently felt moments of **joy**

**100%**
Felt they spent **quality time** with people they cared about

**100%**
Felt they had **someone who would listen** when they needed to talk about worries and problems

**100%**
Agreed CCF helped them learn ways to **manage their emotions**

## Support for loneliness and anxiety, plus information on bereavement support services may benefit bereaved families

**1 in 2**
Felt **lonely** (50%)

**3 in 4**
Recently felt **anxious** (75%)

**1 in 3**
Didn’t know of **grief and bereavement support services** they could use if they wanted to (33%)

Despite the challenges of bereavement, families are showing strong emotional and practical resilience. The consistent experiences of joy, connection, support, and day-to-day functioning suggest that families are drawing on effective coping strategies, likely strengthened by strong and healthy relationships and support networks.

Although the small sample size limited the use of statistical analysis to identify priority needs, the factors below received the lowest scores from bereaved families, indicating areas with potential for meaningful improvement. These findings highlight opportunities to strengthen emotional support and increase awareness of available resources for bereaved families, which may help families feel more connected and supported during this difficult time.

“I would've never known that there's so much support from this organization. **You have helped our family so much with adapting to our new ‘normal’**. This organization honestly thinks and caters for the big and small impacts that families face and we will be forever grateful. **You have provided more time for us as a family**.”

*—CCF Wellbeing Survey Respondent*
*(From the On-Treatment Families measurement group)*

“Knowing that there is a Foundation out there to support our family is so special, **knowing they are a phone call away** and they have lots of understanding and knowledge to support when/if needed.”

*—CCF Wellbeing Survey Respondent*
*(From the Off-Treatment Families measurement group)*

# Key Findings: Impact of CCF Services

The following section outlines the impacts arising in 2024-2025 from CCF services.

- How Families Access Services through CCF
- CCF's Most Helpful Information for Families
- Support of Family Support Coordinators
- Support of Counsellors
- How Families Connect with CCF

*Factor questions were asked on a Likert scale of 1–7, where 1 = Strongly Disagree, 4 = Neutral, and 7 = Strongly Agree. Positive responses were all that responded 5 or higher, indicating that respondents at least "somewhat agreed" with the statement. Attribution questions were asked on a Likert scale of 1-5, where 1= Not at all, 2= A little bit, 3 = Somewhat, 4 = Very much, and 5 = Completely. Positive responses were all that responded 2 or higher, indicating that respondents attributed at least some of their status with respect to that factor to CCF.*

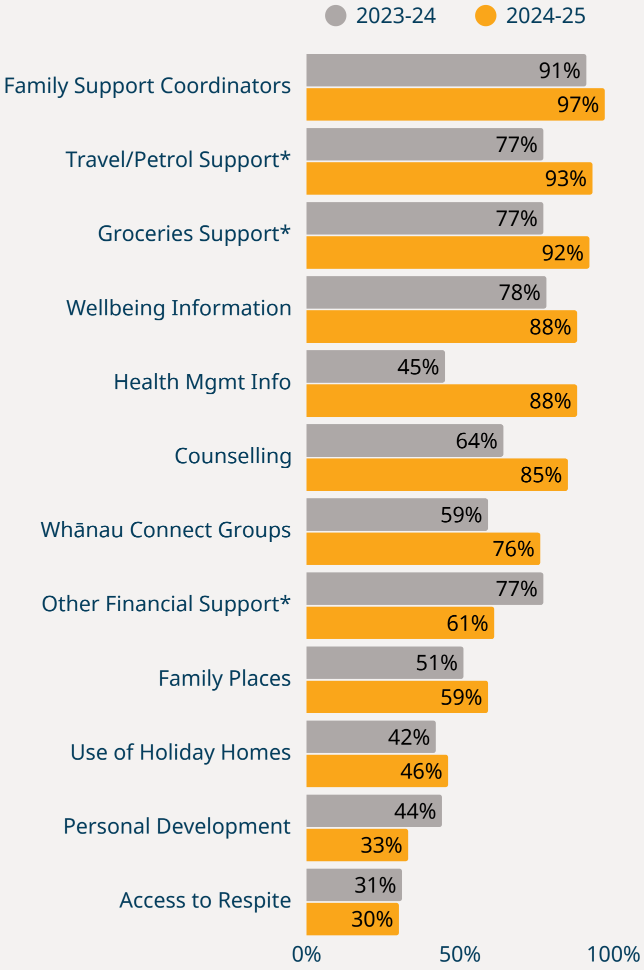
# CCF Fosters Higher Access for Families to Access Services

**88%** Of families agreed CCF helped them **access support services**

When asked how much CCF has helped with accessing certain services, **respondents most utilised FSCs, followed by practical support on travel, petrol and groceries, and wellbeing and health management information** (the latter including webinars, pamphlets, booklets, and other resources). This reflects data that CCF has helped families manage the overwhelming amount of information on their child's diagnosis. Further, those accessing health management information through the help of CCF has almost doubled from the previous period (45%) to the 2024-25 period (88%). **Positively, CCF has fostered higher access for families across nearly every service since the last reporting cycle.**

Services with lowest access through CCF included respite, personal development, and use of holiday homes. Fewer than half of families agreed CCF helped them access these services, in line with previous years (except for personal development, which saw an 11% drop). Lack of access to respite care is an enduring finding across several years of measurement, and continues to be an opportunity for exploration and improvement.

**How much has Child Cancer Foundation helped with accessing the following services?**



## Access to Bereavement Services

Of the bereavement families, **33% did not agree they knew of grief and bereavement support services** they could use if they wanted, but these individuals agreed they had used bereavement support services offered by CCF. Out of the whole measurement group, only one had not used bereavement support services offered by CCF, however this respondent agreed they did know of grief and bereavement support services they could use if needed. Noting the small sample size of this measurement group (n=7), these somewhat contradictory findings may paint a picture of families requiring more or different bereavement services compared to what CCF currently offers, but are inconclusive without further measurement to add to the dataset.

**In 2024-25 measurement, "Financial support" was further broken out into "Travel/Petrol Support", "Groceries Support", and "Other Financial Support", explaining the lower percentage for "Other Financial Support" in 2024-2025. The 77% for "Financial Support" in 2023-2024 was used in this graph in lieu of more granular data.*

# Voice of Our Families:
# Most helpful Information from CCF

When asked, **“What has been the most helpful information CCF provided to help you manage your child’s cancer diagnosis?”**, families primarily took the opportunity to reiterate the benefit of the services outlined on the previous page. Their voices are shared below, categorised by service and measurement group.

◆ New Families ● On-Treatment Families ▲ Off-Treatment Families

### Family Support Coordinators

- ◆ *Our CCF support person is very caring so we appreciate all her support.*
- ◆ *The gentle check in regularly.*
- ● *[Our FSC’s] phone calls have been the most helpful.*
- ● *The presence of Family support Coordinator is the most important they help us in many ways.*
- ● *Family Coordinator and being informed about things that are available if we need them*
- ▲ *[Our FSC] listening/ sharing stories from other families.*
- ▲ *Genuine caring conversations about what to possibly expect.*

### Counselling

- ◆ *Info re access to funded counselling.*
- ◆ *Bit of counselling feelings which has been really nice.*
- ● *Access to counselling support.*
- ● *Psychosocial support (PSS).*
- ▲ *Access to therapy / counselling for our child.*

### Whānau Connect

- ● *Connect[ing] with other family and events.*
- ● *Families with similar situations, how other families are coping with cancers.*

### Beads of Courage

- ▲ *I think the beads program is phenomenal. 11/10 for this program. So brilliant and amazing and effective and so loved by my child.*

### Financial & Transport Support

- ◆ *Passing on documents to our support team for a mobility van.*
- ● *Ambulance & disability parking sorted for us.*
- ● *Financial applications to WINZ [Work and Income New Zealand].*
- ● *Travel support to starship hospital.*
- ▲ *Petrol cards and supermarket deliveries to take those pressures off.*
- ▲ *Flying our oldest boy ... when we were sent home from Starship as treatment wasn't working, we all needed to be together.*

### Wellbeing/Health Management Info

- ◆ *Initial wellbeing guides through chemo.*
- ◆ *Connecting us with make a wish.*
- ● *Website and info sheets.*
- ● *The initial booklets of information.*
- ● *Booklets for siblings of a child with cancer.*
- ● *Getting us in touch with true colors.*
- ▲ *Even with everything being super overwhelming with loads of paperwork and information, our representatives from CCF has been phenomenal in their support of our family.*

### Use of Holiday Homes

- ▲ *The chance to stay in the holiday house in Arrowtown was very precious.*

“The initial diagnosis was overwhelming and then everything died away and **CCF were the only ones who stayed in contact**. Being there, always showing up, the love and care. I honestly don't know that I would've been able to be kept sane if I didn't have someone I could turn to. Never judged. **Just help when we needed it the most and we were so grateful**.”

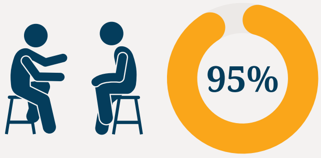
*—CCF Wellbeing Survey Respondent*
*(From the Off-Treatment Families measurement group)*

“We love that **there is also help for siblings**.”

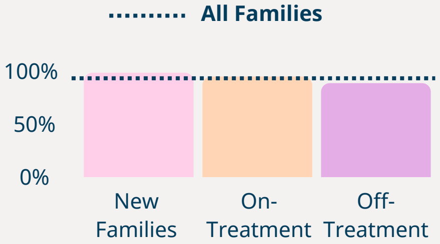
*—CCF Wellbeing Survey Respondent*
*(From the Off-Treatment Families measurement group)*

# Family Support Coordinators are at the heart of CCF’s Impact

Each family referred to CCF is put in touch with a dedicated Family Support Coordinator (FSC); someone who provides holistic support across each family’s cancer journey. This approach puts the child and their family at the centre of care, and allow for one consistent relationship throughout different treatments, stages, locations and medical staff. Below are the results of 2024-2025 measurement and written feedback from families.



Felt treated with respect by their Family Support Coordinator



Families were overwhelmingly positive regarding their FSCs, both in quantitative and qualitative data. The vast majority of families felt treated with respect by their FSC, ranging from 100% for new families to 90% for off-treatment families. Written feedback on FSCs was also incredibly positive, with several families citing FSCs as the reason they were able to cope. Families appreciated how FSCs were always present and brought with them warmth, empathy, understanding, emotional as well as practical care, and a wealth of information from their experience. This spread into other open feedback, with FSCs frequently listed in responses regarding CCF’s most helpful information, what helped families with resilience, and CCF’s overall impact. **Results suggest FSCs are the heart of CCF’s impact, being the first point of call for support and a gateway to accessing CCF’s other services and initiatives.**

*“[Our FSC] has been so good at just being there which is all we need currently. She has informed us of what is available, she is accessible whenever needed and is in regular contact to check in. Most importantly she has always respected our space and what we need - she has not pushed anything on us but offered services should we need them.“*

—Survey Respondent (From the New Families measurement group)

*“So many professionals coming and going it was hard to remember who was who. Some introduced themselves then went away. [Our FSC] kept in touch regularly- and I knew who she was and felt so supported by her.”*

—Survey Respondent (From the On-Treatment Families measurement group)

***“**I was fortunate to have the most understanding empathetic, genuinely caring Support Co ordinator. [Our FSC] is a breath of fresh air. I have received booklets about self care and information about [my child’s] diagnosis. I have had conversations with [our FSC] that have lifted my spirits. She has talked about the services that can be accessed if needed.”*

—Survey Respondent (From the Off-Treatment Families measurement group)

*“They have supported me in times when I couldn't support myself. [Our FSC] specifically was always there for me if need be and always messaging or ringing to check in. She was a god send! She also went the extra mile for us some days and made sure my baby and I felt well supported. She gave us what we needed too and that was to feel like we had someone who cared. I will forever be grateful to her and to everyone including those behind the scenes that make this foundation work.”*

—Survey Respondent (From the Bereaved Families measurement group)

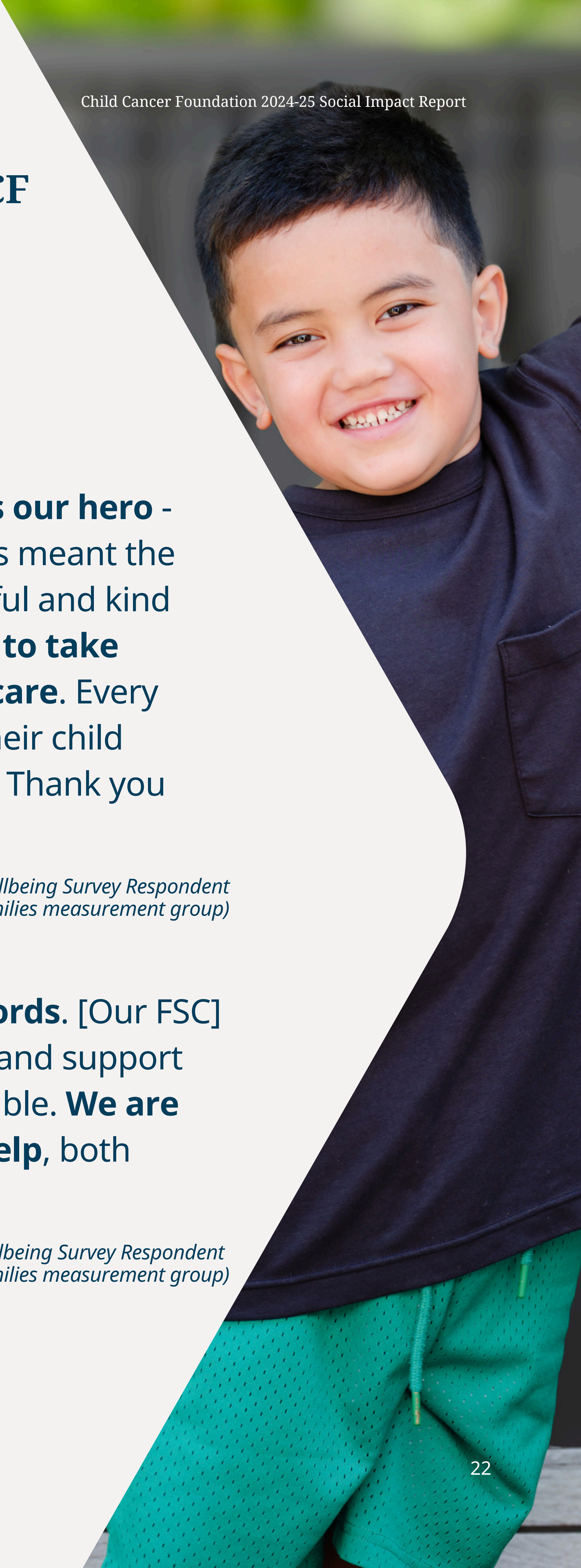
# FSCs Described by CCF Families

“**Our family coordinator is our hero** - her empathetic support has meant the world to us, she is thoughtful and kind whilst still **encouraging us to take charge of our daughters care**. Every family facing cancer with their child deserves [an FSC like ours]. Thank you CCF.”

*—CCF Wellbeing Survey Respondent*
*(From the New Families measurement group)*

“**I'm not sure there are words**. [Our FSC] is amazing and the service and support CCF could offer was invaluable. **We are forever grateful for the help**, both holistically and financially.”

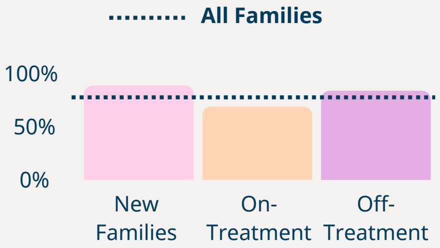
*—CCF Wellbeing Survey Respondent*
*(From the Bereaved Families measurement group)*



# Families were Supported by Counselling Services Through CCF

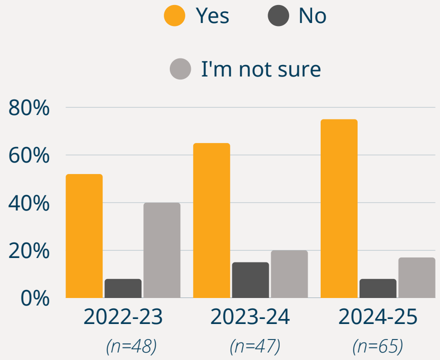
Supporting a child with cancer affects nearly every part of family life, as families navigate complex challenges throughout the journey that can lead to considerable psychological distress. Counselling services allow families to connect in with professionals who can support them through these complex challenges emotionally as well as mentally. As seen on the previous page, only 26% of families accessed counselling services, slightly lower than the 29% of families accessing counselling the previous year.

Felt the counselling services met their needs at least a little bit



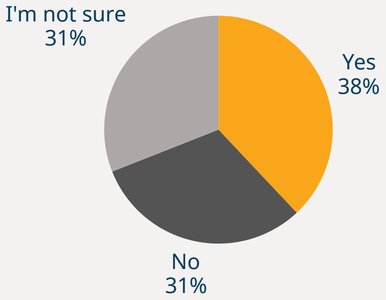
Of those accessing counselling, 80% of families felt the services met their needs at least to some extent, and 76% reported CCF helped them access these services to at least some extent; these figures are slightly lower than the previous year's 83% and 81% respectively. The majority of written feedback around counselling was positive, with some comments around being unable to access counselling services for their family. This data indicates CCF largely continues to provide access to helpful counselling for families.

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



**Proportion of CCF Families not Offered Access, who knew how to Access Counselling Services**

n= 16

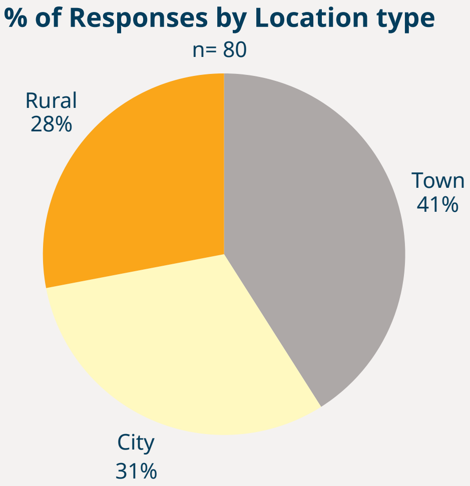


*"We are fortunate that we are managing financially, the biggest help for us have been the counselling sessions, which have been so helpful to me."*
*—Survey Respondent (From the New Families measurement group)*

*"We once asked for support for counseling services for my husband and were told nothing was available."*
*—Survey Respondent (From the On-Treatment Families measurement group)*

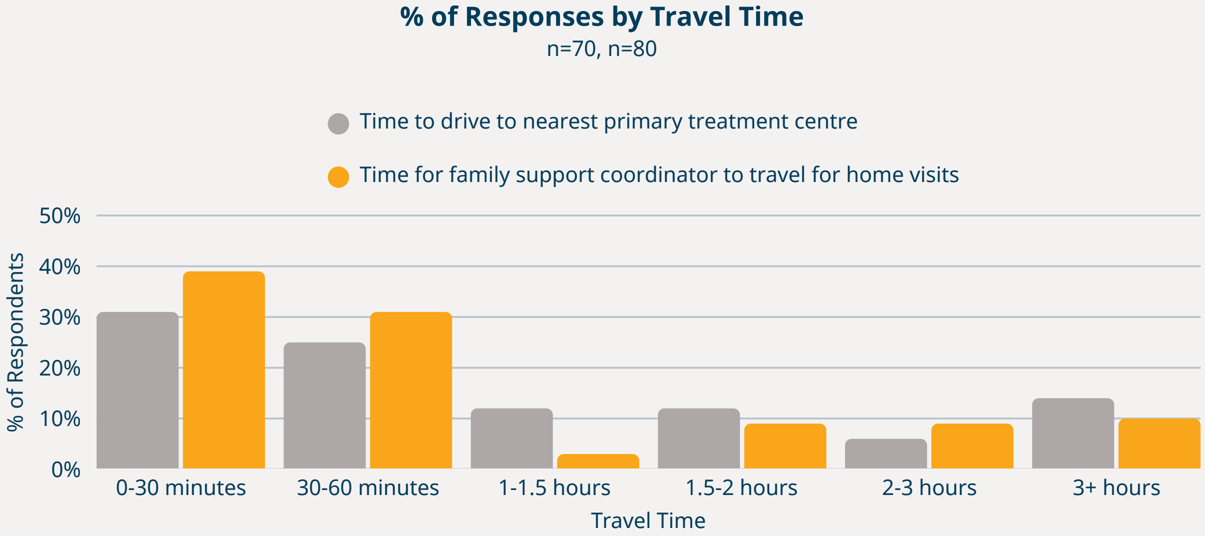
*"We were very grateful to receive funding for counselling support for two family members."*
*—Survey Respondent (From the On-Treatment Families measurement group)*

# CCF Serves Families Across Aotearoa New Zealand



**One of CCF's core tenets is its commitment to serve everyone in Aotearoa, not just those in urban populations**.
It doesn't matter where a family is; CCF is there for them. This is reflected in the make-up of CCF families responding in the 2024-2025 measurement, with almost 3 in every 10 respondents (28%) responding that they were living in a rural area. This is a high proportion in contrast to Aotearoa New Zealand, where only 16% live in a "rural" area.[4]*

**Family Support Coordinators are closer to home**
This commitment to serve all of Aotearoa New Zealand without leaving anyone behind is further evidenced by how CCF has structured its services through Family Support Coordinators (FSC). FSCs not only directly support families, but are also the gateway for families to further access other supports and services: FSCs are the service CCF has helped families access the most (97% on page 18), and the service through which CCF has been able to support families the most across the last 6 months (84% on page 25). As seen in the graph below, FSCs tend to have shorter commute times for home visits, as they are located closer to family homes compared to primary treatment centres. These shorter commute times enable CCF to provide more accessible and frequent home visits, particularly for families in rural areas. This further supports timely intervention and continuity of care for families.



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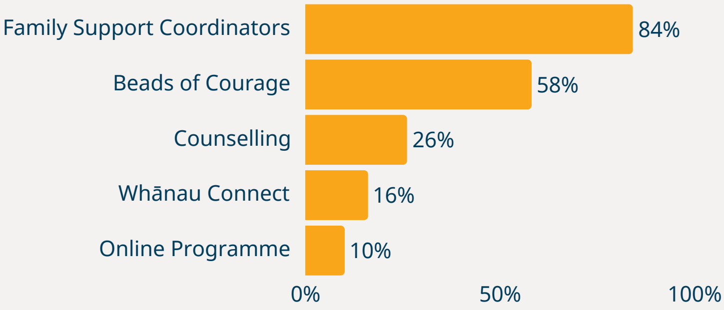
* Noting a different classification scheme is used for the national statistic; 5 classifications (Major urban area, Large urban area, Medium urban area, Small urban area, Rural), compared to 3 classifications used in CCF survey (City, Town, Rural).[4]

# How Families Connect in with CCF

Families were asked **in the past six months, in which ways did they connect or receive support from CCF**. Family Support Coordinators were most common, followed by the Beads of Courage Programme, counselling, Whānau Connect, and online programmes.

**Connection with or support from CCF in the last 6 months**



**90%** of families surveyed had a connection with or support from CCF in the last 6 months.

**Whānau Connect** Groups are an initiative set up by CCF, with 19 active groups across New Zealand at time of writing. The Groups connect families who are going through a child's cancer journey, and provides a space for them to share their experiences and support each other.

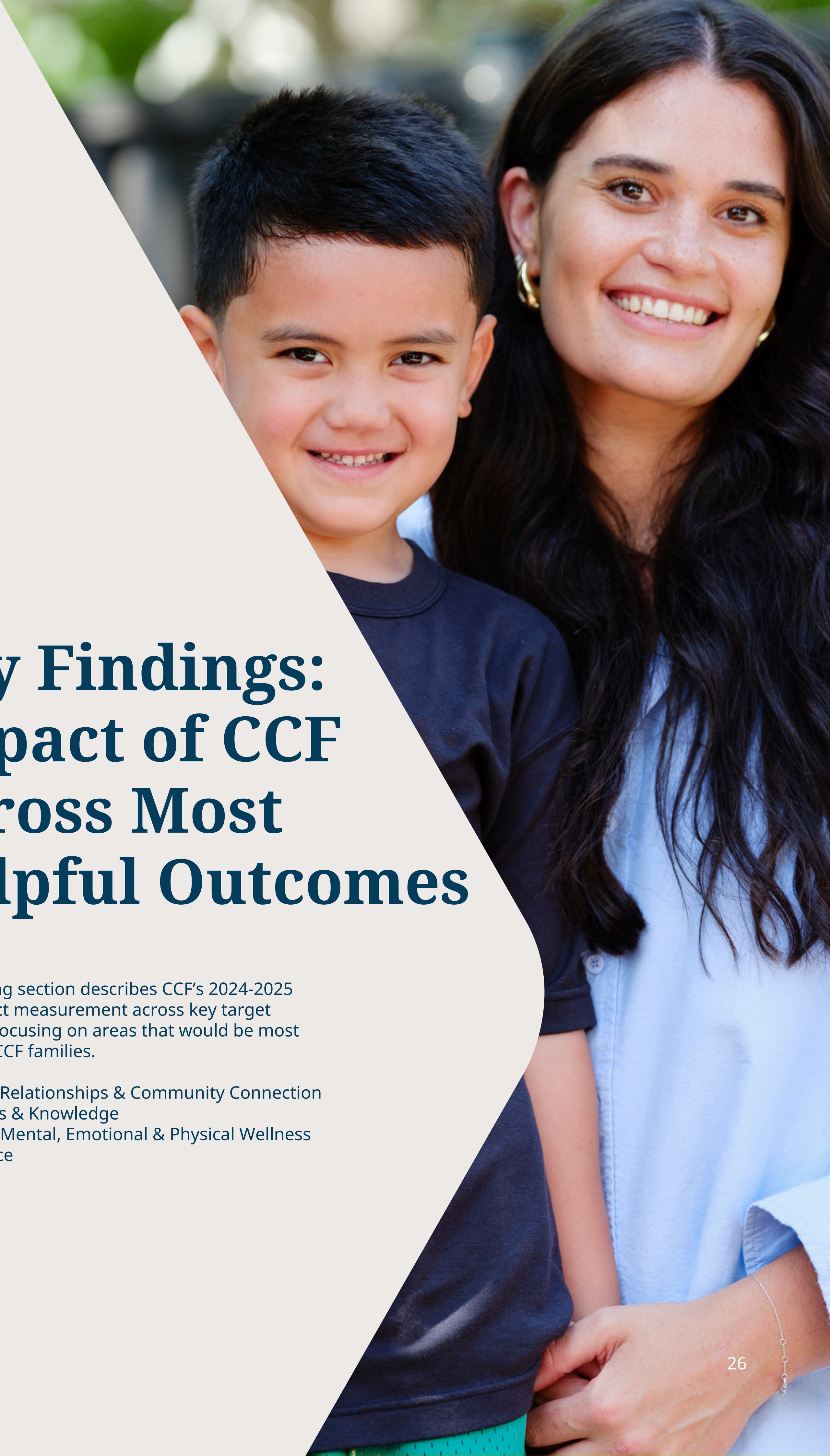
Whānau Connect Groups helps bring to life the importance and benefits of connecting with other family and whānau going through the same journey. This is especially important because due to the relatively rarity of child cancer, it is unlikely families will know of other families on the same journey through their conventional support networks. Written feedback heavily emphasised the importance of talking with families in similar situations, with several explicitly celebrating Whānau Connect for their work.

With just over half of surveyed families accessing the Beads of Courage programme (58%), there was extensive praise across written feedback questions, especially around helpful information from CCF, as well as overall impact. Multiple responses used the word "brilliant" to describe the Beads of Courage Programme, with several highlighting how the beads helped their child and family keep their focus positive and symbolise the child's strength and bravery, with the programme having particularly positive impact on the child.

The **Beads of Courage Programme** helps physically signify the journey of each child's cancer treatment, with each bead representing a step, whether it be each chemotherapy treatment, injections, scans, hair loss, isolation, or a milestone, such as completion of treatment.

*"The beads are fantastic. When I look at all of the beads my son has got I think of all he has been through and how proud I am of him and how he has handle it. It also will give him something to look at in the future and know each of those beads was shows his cancer journey and to remind him if he can go through all that he can overcome anything that life throws at him."*

—Survey Respondent (From the New Families measurement group)



# Key Findings: Impact of CCF Across Most Helpful Outcomes

The following section describes CCF’s 2024-2025 social impact measurement across key target outcomes, focusing on areas that would be most helpful for CCF families.

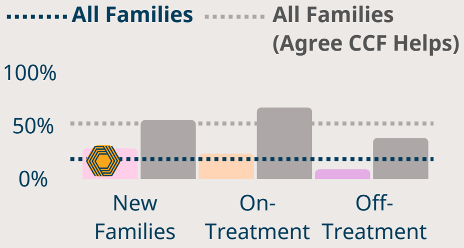
- Healthy Relationships & Community Connection
- Life Skills & Knowledge
- Positive Mental, Emotional & Physical Wellness
- Resilience

# What Helps Most: Healthy Relationships & Community Connection

As seen across the measurement group findings, **families are generally feeling strong in their relationships and support networks**, with similarly high attribution scores indicating CCF helps them with this. The only exception was new families for the relationships with partner factor, which was a priority need. Further investigations into this factor and wider outcomes are outlined on this page.

**21%** Felt their **relationship with their partner was struggling** due to pressure from cancer diagnosis

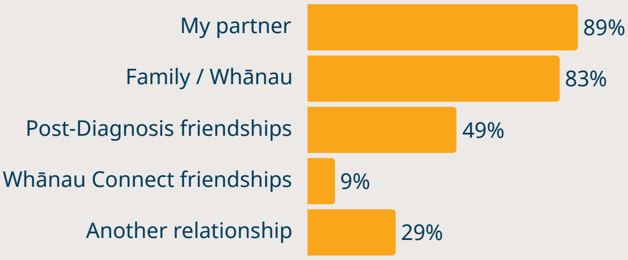
**56%** Agreed CCF helped them manage this



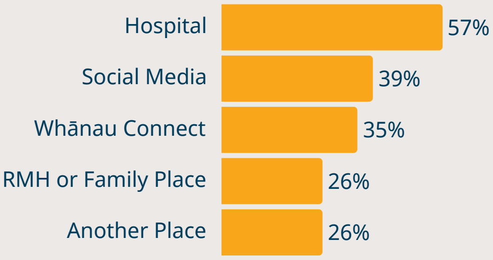
⬡ *A priority need and therefore biggest opportunity for improvement for these families.*

**Despite being a priority need for new families, there is overall improvement from prior years**
Positively, when comparing all CCF families responding in 2024-25 to the same group in the previous year, there was a 10% reduction in feeling one's relationship with their partner was struggling due to pressure from the cancer diagnosis.

**People or relationships in respondents' life who understand how they feel**
(n=35)



**Places where families connected with other caregivers through CCF**
(n=23)



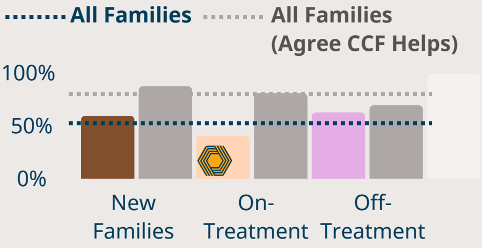
**Families are surrounded by people who understand how they feel, connecting with other caregivers in person and online**
Positively, for those responding to the question around people who understood how they felt, one's partner was most commonly included (89%), closely followed by family / whānau. When connecting with other caregivers through CCF, the majority of those responding to the question connected in person, at hospital (57%), then through social media like Facebook groups (39%).

# What Helps Most: Life Skills & Knowledge — Emotional Acceptance

Emotional acceptance emerged as a lowest-scoring factor for the on-treatment measurement group within the *life skills and knowledge* outcome. Understandably, while only roughly 1 in 2 families felt they were able to emotionally accept their child's cancer diagnosis, this year saw a +12% increase in this factor across families (new, on-treatment and off-treatment) compared to the previous measurement period. While off-treatment families were most likely to feel emotional acceptance (63%), only 41% of on-treatment families agreed with this statement. New families saw the biggest shift (+13%) compared to last year, and their agreement that CCF helped with this rose to 88%, suggesting CCF has continued to improve support in this area, especially for new families.

**54%** Felt they were able to emotionally accept their child's cancer diagnosis

**80%** Agreed CCF helped them with this



*A lowest-scoring factor and therefore biggest opportunity for improvement for these families.*

*"My CCF support person has given me strength and encouragement to accept this diagnosis, to stay positive and carry on."*

—Survey Respondent (From the Off-treatment Families measurement group)

**Bereaved Families responded with high levels of emotional acceptance to their child's passing**

**100%** No longer find it difficult to accept their child's death

**75%** Agreed CCF helped them with this

Findings from bereaved families indicate an extraordinary amount of resilience and emotional acceptance, with none of the 7 families agreeing with the statement "I have difficulty accepting my child's death", and 75% agreeing CCF helped them with this.

The strength of these bereaved families shine through in their written feedback, as well as other things that helped them find acceptance, including their support networks, care of the medical staff, their other children, and CCF's support.

*"We have an amazing village around us. Also I know I did everything I could for my daughter and so did the Medical team. This helps with acceptance."*

*"Accepting that the medical staff did everything they could.  Support from CCF and friends, whānau.  Our other child, we have to keep living for him."*

*—Survey Respondent (From the Bereaved Families measurement group)*

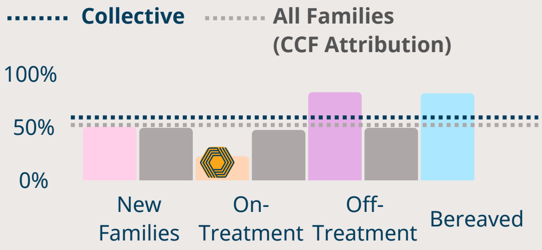
# What Helps Most: Positive Mental, Emotional & Physical Wellness

A number of lowest-scoring factors and priority needs were found under the *mental, emotional and physical wellness* outcome. This page outlines these factors, as well as how much help families felt they received from CCF across each topic.

**Fewer opportunities to maintain physical wellness for those new and active in cancer journey**
Practical but time-consuming activities like maintaining physical wellness can tend to fall by the wayside, especially in the face of treatment schedules and trying to keep up with life. Understandably, the new and on-treatment families least felt they had the opportunity to maintain their physical wellness. Further half of respondents agreed CCF helped with this. These findings align with CCF's programmes focusing more heavily in other areas.

**51%** Felt they had the opportunity to maintain their **physical wellness**

**50%** Agreed CCF helped them with this

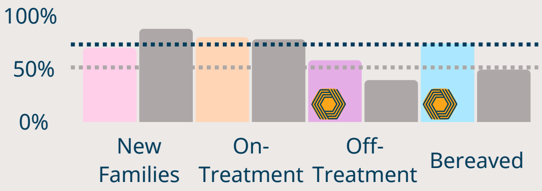


**Feelings of anxiety and helplessness are prevalent among families across the cancer journey**
Feelings of anxiety were present across families and were lowest-scoring for off-treatment and bereaved families, indicating these families may need focused support to deal with these feelings. On-treatment families least agreed that they felt helpless, which may reflect a sense of action or control associated with this stage in actively treating their child's cancer diagnosis.

**Positively, the majority of respondents across both factors agree that CCF have helped them manage their anxiety and feelings of helplessness.**

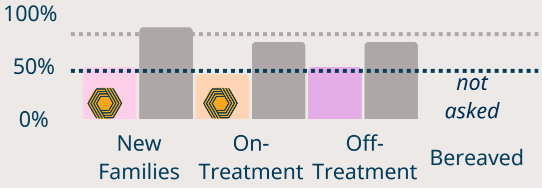
**72%** Recently felt **anxious**

**70%** Agreed CCF helped them manage this



**48%** Felt **helpless** at times

**78%** Agreed CCF helped them manage this



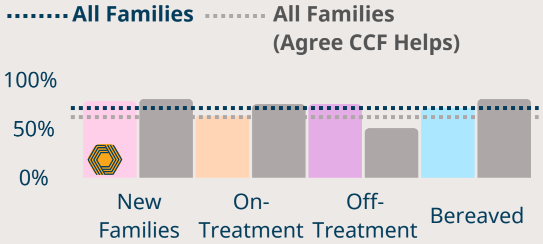
⬢ *A lowest-scoring factor or priority need, and therefore biggest opportunity for improvement for these families.*

# What Helps Most: Resilience

Under the *resilience* outcome, one factor presented itself as a priority need for New Families. This factor was around adaptability, namely recovering quickly after setbacks. This page sets out further detail on this factor, including a breakdown of scores to pinpoint how new families are responding.

67% Agreed that they tend to **recover quickly after setbacks**

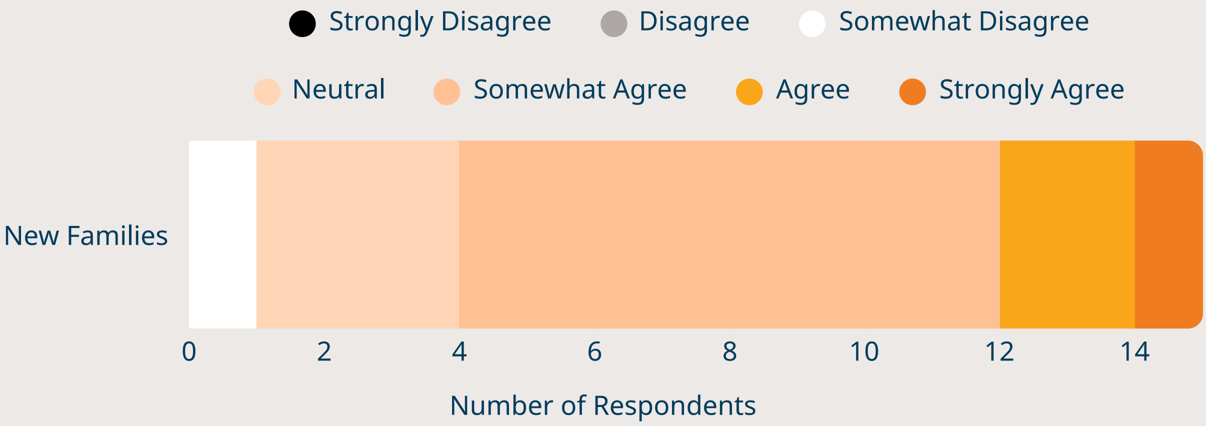
65% Agreed CCF helped them with this



*A lowest-scoring factor or priority need, and therefore biggest opportunity for improvement for these families.*

**Despite higher general agreement, new families only 'somewhat' felt they recovered quickly after setbacks, revealing a priority need**
Although new families were more likely to agree with the above statement compared to other families in the above graph, a breakdown of exactly how new families responded reveals that a large majority only 'somewhat' agreed. This is reflected in a lower average score compared to other families (4.93 compared to average of 5.16 across all families). Further, correlation analysis revealed this factor to be a priority need for new families. Altogether, findings indicate there is still room to improve support for new families to recover quickly after setbacks.

**All New Families responding to the statement 'I tend to recover quickly after setbacks'**



# What Helps Most: Resilience, in Families' Own Words

When asked **'What else has helped you remain resilient through your family's journey with cancer?',** families most often emphasised support from family, friends and community. Other common themes included faith, healthcare and support services, strength drawn from their relationship with their children, a positive mindset including enjoying the present moment, and counselling. A smaller number mentioned having previous medical or caregiving experience, or that work and daily routines helped provide balance and stability.

◆ New Families ● On-Treatment Families ▲ Off-Treatment Families ■ Bereaved Families

### Family, Friends & Community

- ◆ *The support of my parents, the support of a wide network of friends.*
- ◆ *Friends, family and community support has been amazing - this has helped a lot and has meant we have not had to access many of the services available.*
- ● *Our village and leaning on others when we need to.*
- ● *Help and support from family and friends.*
- ▲ *My partner and our immediate family unit.*
- ▲ *Well wishes, texts from people. The support of our community.*

### Relationship With their Child/ren

- ◆ *Just knowing my boy has a positive attitude and him knowing I'm there for him 100%.*
- ● *If our daughter has to go through what she has to, we need to be even stronger for her so she doesn't have to worry about our feelings.*
- ▲ *Focusing on spending quality time with [my child] and creating good memories...I use this as an opportunity to be the best mum I can. I know that I can't control if he relapses or not but I can control what kind of parent I am and the worst thing I can do for him is live in fear and mope around.*

### Counselling

- ◆ *Precious therapy.*
- ● *Having regular psychologist sessions.*
- ● *Counselling with True Colours.*

### Faith & Spirituality

- ◆ *My faith.*
- ● *Our faith is what has got us through.*
- ● *Our faith in the Lord Jesus Christ.*
- ● *My belief, I am a Christian. I know I can't control anything.*
- ▲ *My faith, my church, family and friends.*
- ▲ *My family's strength and faith.*

### Support Services & Healthcare Team

- ● *Being surrounded by medical professionals that are thorough in providing good healthcare to our child.*
- ● *The amazing care team at Starship.*
- ▲ *Talking with our family support worker.*
- ▲ *The hospital staff, all the opportunities offered by CCF and Ronald McDonald and Canteen.*

*We would not have been able to cope without the support from CCF.*

### Positive Mindset

- ▲ *The knowledge that we cannot change my circumstance or his diagnosis but we can try make everyday as beautiful as we can and enjoy and be grateful for the good days we do have.*
- ▲ *Being flexible and trying to retain a sense of humour. Enjoying big and little things. Celebrating all the good things. Trying to be positive.*

“Such an **awesome service keep up the amazing mahi you do**, you may not realize the impact you have on whanau lives.“

*—CCF Wellbeing Survey Respondent*
*(From the Bereaved Families measurement group)*

“You are amazing and sadly, so needed. **Keep doing what you're doing** you incredible people!”

*—CCF Wellbeing Survey Respondent*
*(From the Bereaved Families measurement group)*

“**We have so much aroha** for who you are and the way you support whānau navigating this really shitty time, this is not a club any of us want to be apart of but man **what a privilege it is to know some incredible people are in your corner** < 3”

*—CCF Wellbeing Survey Respondent*
*(From the On-Treatment Families measurement group*

# Bringing it Together: Holistic Impact and Next Steps

The following section sets out final commentary from 2024-2025 families on CCF, and concludes the report.

- Feedback for Improvement
- Holistic Impact
- Reflections and Recommendations
- Measurement Approach and About Huber Social
- CCF’s Social Impact Model

# Voice of Our Families: Feedback on Improvements

When asked **‘Do you have any feedback, suggestions, or improvements for Child Cancer Foundation?’**, families most often highlighted the need for better awareness of support — both knowing that support is available and understanding what specific services they can access. Practical support was mentioned by several respondents. Others gave feedback about Family Support Coordinator relationships, with some noting the impact of high turnover and COVID-19 restrictions on consistency, and one suggesting a process for feedback or changing caseworkers. Several respondents expressed only positivity and gratitude for CCF’s support. A smaller number requested more support for those in remote areas, and more opportunities for connection with other families.

In addition, families identified several technology needs while away from home for treatment, including access to devices like tablets or laptops, entertainment options for their children, and advocating for better internet connectivity in hospitals.

◆ New Families ● On-Treatment Families ▲ Off-Treatment Families ■ Bereaved Families

### Awareness of & Access to Timely Support

◆ *I think a list of exactly what parents or children are entitled to would be a really good thing to see at the beginning of the journey because I'm still not 100% sure what services other then counseling services.*

● *...this survey pointed out many many things we have not been offered...*

▲ *I wasn't told about Child cancer foundation and the help they could give us till three months into my daughter’s treatment.*

■ *As a family that doesn’t ask for 'hand outs', we weren’t fully aware of what was available during the time of treatment.*

■ *The Child Cancer wards should be more encouraging to families to join. It's so overwhelming at the beginning...But what they offer is invaluable and unmeasurable!*

### Practical Support

◆ *Offer groceries and petrol vouchers - would help a lot particularly as a solo parent.*

● *Maybe a cleaner for when I got home? But I was so excited to go home I didn't think to ask.*

■ *...things like vouchers for food/petrol...as a family, we would never have asked for these although they would have been incredibly helpful...*

### Family Support Coordinator Relationships

● *High turnover of family support workers and lack of consistency around this...My child was diagnosed a year ago and in that time we have had 4 family support workers and each time you start to build a new relationship and go over everything and then they leave and you have to start from scratch again.*

▲ *I felt that I wasn’t heard...My top suggestion is find a way for families to provide feedback on their caseworkers ...Or perhaps there could be a pathway to change caseworkers without causing offense. Like an acknowledgement upfront that sometimes we don't click and CCF says it's ok to change.*

■ *Initially, we did not find CCF very helpful. However, this may be in part due to COVID restrictions and limited contact with our Family Support coordinator at the time.*

### Gratitude and Positive Feedback

● *Nothing really, just thank you for what you do.*

▲ *Thank you so much for everything you do and continue to do.*

■ *Just being aware of support if needed has helped.*

# In Their Own Words: A Closer Look at Overall Impact

When asked **‘In your own words, how has CCF had an impact on your life?’**, families overwhelmingly responded with gratitude and appreciation for CCF’s support. Many expressed gratitude for the emotional support they received, as well as the reassurance of having someone they could rely on for help when needed, with some specifically mentioning their family support coordinator. Practical and financial help was also widely appreciated, helping to ease day-to-day pressures. Several families shared how child-focused initiatives, particularly the Beads of Courage programme, stood out as meaningful and uplifting for their children.

◆ New Families ● On-Treatment Families ▲ Off-Treatment Families

### Emotional Support

- ◆ *It's all very new, and appreciate the conversations thus far to help with feeling at those moments.*
- ◆ *Receiving the moral, emotional and financial support... Am truly grateful for foundations such as CCF that help in these circumstances for all children and families going through these tough journeys.*
- ● *CCF makes me feel that I am not alone though the journey.*
- ▲ *CCF was a huge ray of sunshine in a very dark period of our lives - offering hope and support that will forever be appreciated.*
- ▲ *The child cancer foundation has been incredible and a massive resource. Every body I have dealt with has been so kind and understanding about the worst thing that has ever happened to our family.*

### Practical and Financial Support

- ● *They have given us support that has allowed us the confidence to focus on our daughters care...*
- ● *They've provided an immense external support, including offering things that we didn't know we needed at times.*
- ▲ *We also really appreciate the small financial help we have received so we can look after our son and not worry about some bills.*
- ▲ *Having car parking available at CCF also really helped us logistically during hospital visits...*
- ▲ *The groceries, petrol vouchers and holiday home were all wonderful.*

### Knowing Someone is There when Needed

- ◆ *Just being aware of support if needed has helped.*
- ● *CCF had a big impact in my life since I met [our family support coordinator] she is not just a family coordinator for us because we became friends.*
- ▲ *The comfort in knowing we have someone there to talk to has been calming and we are so thankful for our support worker.*
- ▲ *At initial diagnosis, CCF were a small glimmer of light in the darkness. I would look forward to check in phone calls from our wonderful Support Coordinator. These really kept Me going.*
- ▲ *..the initial contact, offers of support and knowing someone was there if we needed help was incredibly valuable.*

### Child-focused Initiatives & Beads of Courage

- ◆ *Bead programme.*
- ▲ *I think the beads program is phenomenal. 11/10 for this program. So brilliant and amazing and effective and so loved by my child.*
- ▲ *The beads and trips to butterfly creek were especially appreciated by [my child].*
- ▲ *[My child]’s biggest joy though was his Make a Wish...He still talks about it.*

# CCF 2024-25 Reflections and Recommendations

This page outlines reflections and recommendations from 2024-25 measurement, as well as progress from 2023-24 reflections and recommendations. Colour-coding indicates where a recommendation is most relevant for families at a particular stage on their cancer journey.

◆ New Families ● On-Treatment Families ▲ Off-Treatment Families ■ Bereaved Families

## 2024-25 Recommendations

**Emotional Support**

- ● ◆ Assist with feelings of helplessness.
- ◆ Support adaptability skill-building (to recover quickly after setbacks).
- ● Additional support around emotional acceptance.
- ▲ Further support for those experiencing late effects after treatment.
- ■ ▲ Support around feelings of anxiety.
- ■ Support around feelings of loneliness.

**Relationships and Connections Support**

- ◆ Encourage families to prioritise and invest in partner relationships where possible.

**Physical Wellness Support**

- ● Support to maintain physical wellness.

**Counselling and Other Services**

- ▲ ● ◆ Continue to ensure knowledge of how to access counselling. There's an opportunity to continue the positive trend described on the right to ensure all families are offered access to counselling, or know how to access counselling.
- ■ Conflicting responses may indicate more or different bereavement services compared to what CCF currently offers.

■ ▲ ● ◆ **Maximising 5 years' of family voices**

- Draw further insights and increase confidence using CCF's strong foundation of data.

## Progress on 2023-24

**Enable families to practice self-care and assist with feelings of helplessness**

Feelings of helplessness continues as a key area to support, especially for new and on-treatment families.

**Encourage investment in partner relationships**

One's relationship with their partner struggling due to pressures from cancer diagnosis continues to be a priority need for new families.

**Ensure knowledge of how to access counselling**

Positively, families offered access to counselling rose from 65% to 75% (2023-24 to 2024-25), and of those who hadn't been offered, 38% knew how to access it (35% in previous period).

**Support connections between families**

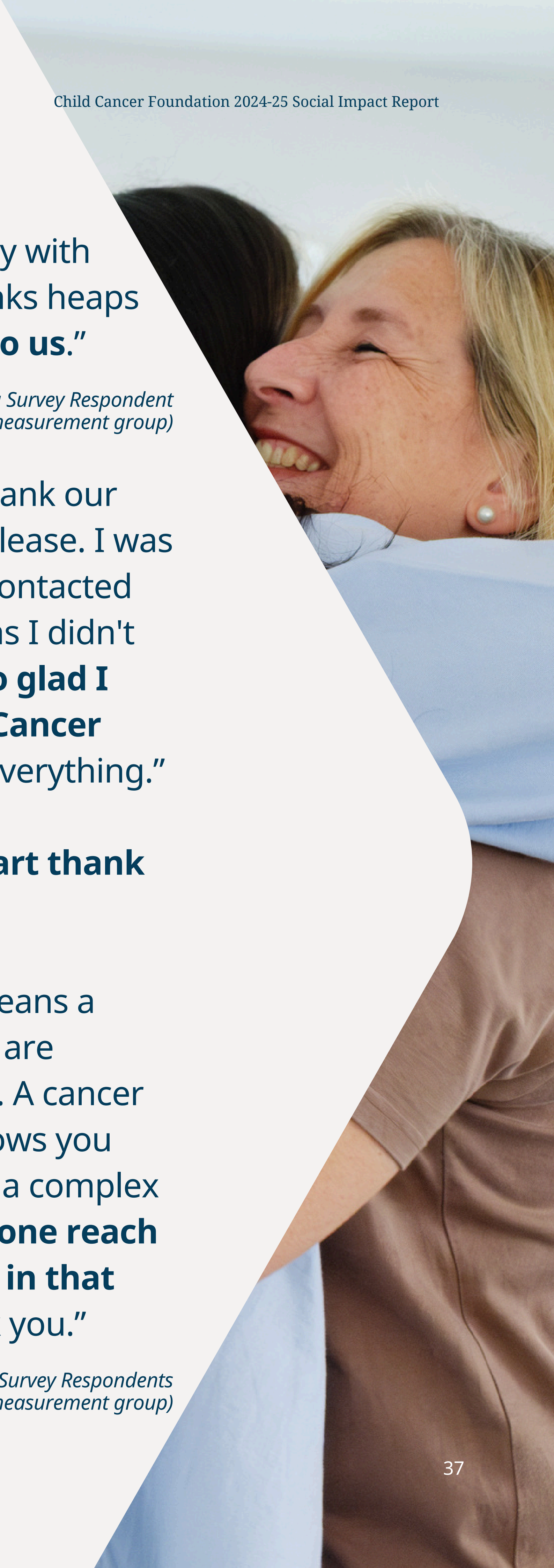
There were no priority needs or lowest scores relating to connections between families in 2024-25.

**Financial literacy and security among families**

The majority of families responded positively in response to statements relating to financial security, however financial and practical support remain highly valued in feedback.

**The power of paired data**

See *Maximising 5 years' of family voices* on left.



“CCF is a big help to the family with cancer patient. I want to thanks heaps **CCF you are a big blessing to us**.”

*—CCF Wellbeing Survey Respondent*
*(From the On-Treatment Families measurement group)*

“Just keep being great and thank our Support Coordinator for us please. I was so hesitant when I was first contacted by Child Cancer Foundation as I didn't know what to expect. **I am so glad I agreed to meet with Child Cancer Foundation**. Thank you for everything.”

“Just thank you, **from my heart thank you.**”

“You do an amazing job. It means a huge amount knowing there are friendly people ready to help. A cancer diagnosis and treatment throws you straight into the deep end of a complex challenge, and **having someone reach out and offer support early in that challenge is massive**. Thank you.”

*—CCF Wellbeing Survey Respondents*
*(From the Off-treatment Families measurement group)*

# Measurement Approach

**Design:** Co-construction workshop with key stakeholders held to determine which capabilities and access to opportunities (outcomes) were most relevant to overall wellbeing (impact) of enrolled families.

**Measurement Tools and Ethical Review:** Data was collected through self-report surveys. The 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 2024 to 31 March 2025.

**Survey Support:** FSCs offered families follow-up consultations, technological assistance, and additional information around the purpose of measurement.

**Sample Size and Response Rate:** From March 2024 to April 2025, 479 surveys were distributed to CCF families, with 80 completed (17% response rate). This includes 73 responses out of 452 surveys sent to families with a recent, current or former diagnosis of cancer (16% response rate) and 7 out of 27 surveys sent to bereaved families (26% response rate).

More information available in the CCF 2024-2025 Technical Report.

# Huber Social

Huber Social holds wellbeing as the measure of success for social impact, with extensive experience measuring the wellbeing of people across the public, private, and social sectors in more than 10 countries.

Huber Social is committed to scientific, cultural, and ethical integrity. To ensure measurement projects ‘do no harm’, all projects are subject to independent review by the Huber Social Ethical Review Board, which is the first and only nationally registered Australian Human Research Ethics Committee (HREC) focused on assessing social impact measurement projects.

As part of this commitment to the integrity of measurement, Huber Social led the drafting of the ‘Handbook for Measuring and Valuing Social Impact’, for Standards Australia, along with our partners Oxford University Blavatnik School of Government and contributors from across Australia, Aotearoa New Zealand, and Singapore. Huber Social is also a member of the UN SDG Impact Assurance Advisory Committee and the UN Private Sector Mechanism of the UN Food and Agricultural Organisation for Sustainable Development.

# References

1. Stats NZ. (2023). *Wellbeing statistics: 2023 (updated).* https://www.stats.govt.nz/information-releases/wellbeing-statistics-2023/

2. Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). *The satisfaction with life scale*. Journal of Personality Assessment, 49(1), 71–75. https://doi.org/10.1207/s15327752jpa4901_13

3. Child Cancer Network. (2019). *Childhood cancer incidence and survival data.* https://childcancernetwork.org.nz/update-to-childhood-cancer-incidence-and-survival-data/

4. EHINZ. (2024). *Urban–rural profile*. https://www.ehinz.ac.nz/indicators/population-vulnerability/urbanrural-profile/.

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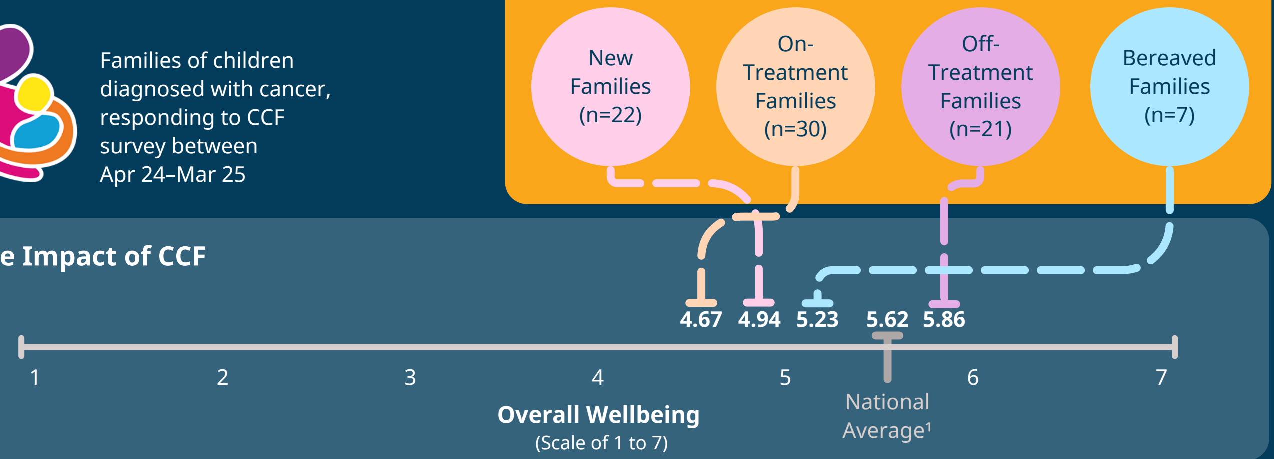
# Factsheet: Social Impacts at a Glance

## Respondents

Families of children diagnosed with cancer, responding to CCF survey between Apr 24–Mar 25

CCF Survey Respondents (n=80; representing 21% of all CCF families)

## The Impact of CCF



**Overall Wellbeing**
(Scale of 1 to 7)

## Impact of CCF Across Families

**90%**
Reported a **positive overall experience with CCF**

**96%**
Agreed CCF helped them have **people in their life who help and support** them

**88%**
Agreed CCF helped them **access support services**

**85%**
Agreed CCF helped them have the skills to **care for a child with a cancer diagnosis**

## Impact of CCF Services

**Family Support Coordinators are at the heart of CCF's Impact**

**95%** Felt treated with respect by their Family Support Coordinator

**Families were Supported by Counselling Services Through CCF**

**80%** Felt the counselling services met their needs to at least some extent

**CCF Serves Families across Aotearoa, not just those in urban populations.**

**28%** of families responded that they lived in a rural area

## 2024-25 Recommendations

- **Further Emotional Support**
- **Further Support for Relationships / Connections**
- **Physical Wellness Support**
- **Accessing Counselling and Bereavement Services**
- **Maximising 5 years' of family voices**

### Most Helpful for New Families:

- Support around **strong partner relationships**
- Coping with feelings of **helplessness**
- Adaptability (support **to recover quickly after setbacks)**

### Most Helpful for On-treatment Families:

- Support around **emotional acceptance**
- Coping with feelings of **helplessness**
- Support to **maintain physical wellness**

### Most Helpful for Off-treatment Families:

- Support with **anxiety**
- Support around **late effects** after treatment

### Most Helpful for Bereaved Families:

- Support for feelings of **loneliness** and **anxiety**
- Further information on **bereavement support services**

For more information, see the *Child Cancer Foundation 2024–25 Social Impact Report.*

*¹Stats NZ. (2023). Wellbeing statistics: 2023 (updated). https://www.stats.govt.nz/information-releases/wellbeing-statistics-2023/*

# Factsheet: How CCF Supports the Strengths of its Families

This page sets out findings across all CCF families responding in 2024-2025 measurement. Key findings on specific measurement groups as well as the impacts of CCF's services, counselling, and tangible assets are detailed on the following pages.

## CCF Families had strong support networks, hope, and quality time and skills to care for their children

**86%**

Felt they had **people in their life who help** and support them and

**96%**

Agreed CCF helped them with this

**85%**

Felt they had things to **hope for**

**79%**

Felt they had the skills to **care for a child with a cancer diagnosis** and

**85%**

Agreed CCF helped them with this

**79%**

Felt they got to spend **quality time with their child/ren**

## Families were holistically supported by CCF in their above strengths, and in the following areas

**90%**

Reported a **positive overall experience with CCF**

**95%**

Felt they were **treated with respect** by their **Family Support Coordinator**

**88%**

Agreed CCF helped them **access support services**

**80%**

Agreed CCF helped them **emotionally accept their child's cancer diagnosis**

Families were particularly strong in their support networks, having hope, and in their care and quality time with their child/ren. The strengths of these families during difficult times shine through in these results. They also reflect the efficacy of CCF's support in these areas of strength, but also across other areas such as emotional acceptance, respect from FSCs, and access to support services.

For more information, see the *Child Cancer Foundation 2024–25 Social Impact Report.*

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# Factsheet: Strengths and What Helps Most for New Families

New families were those who had recently been referred to CCF within the last 3 months before taking the survey, and served as the "baseline" for CCF's impact measurement (although CCF may have already started supporting them at point of measurement). Respondents in the new families category had a wellbeing score of 4.94, trending lower than the previous measurement period (5.57), indicating new referrals in 2024-2025 had joined with lower overall wellbeing compared to previous cohorts.

## New Families felt they had learnt ways to manage their emotions, and agreed CCF helped them manage feelings of anxiety.

**95%**

Agreed CCF has helped them have people in their life who **understand how they feel**.

**89%**

Agreed CCF helped them **manage the overwhelming amount of info** on their child's diagnosis

**89%**

Agreed CCF has helped them manage feelings of **anxiety**

**80%**

Felt they have learnt ways to **manage their emotions**

## Support around strong partner relationships, coping with feelings of helplessness, and adaptability most helpful for New Families

**1 in 4**

Felt their **relationship with their partner was struggling** due to pressure from the cancer diagnosis (24%)

**1 in 2**

**Felt helpless** at times (50%)

**1 in 4**

Didn't agree that they tend to **recover quickly after setbacks** (27%)

Positively, new families showed strength in managing their emotions and having people around them who understand how they feel. The majority of new families also attributed their ability to manage feelings of anxiety and overwhelming amounts of information to CCF. New families had priority needs around partner relationships, coping with feelings of helplessness, and adaptability; support from CCF in these areas would be most helpful for these families.

For more information, see the *Child Cancer Foundation 2024–25 Social Impact Report.*

# Factsheet: Strengths and What Helps Most for Families On Treatment

The on-treatment measurement group included families of children who were receiving cancer treatment at the time of measurement. On-treatment families reported a wellbeing score of 4.67, the lowest out of the current year's measurement groups and trending slightly lower than on-treatment families in 2023-2024 (4.85). This indicates on-treatment families may benefit most from the support of CCF to improve overall wellbeing.

## On-treatment families were strong in their resilience, management of their financial situation, and ability to process their emotions

**90%**
Felt they could **handle many things** at a time

**82%**
Agreed CCF helped them **manage the overwhelming amount of info** on their child's diagnosis

**82%**
Felt they could understand and **manage their financial situation**

**79%**
Felt they had learnt ways to **manage their emotions**

**3 in 5**
Felt their child's cancer treatment was progressing as planned

## Emotional and practical support is most helpful for on-treatment families

Based on data from the 2024–2025 measurement period, statistical analysis of on-treatment family responses did not identify priority needs (factors that are both statistically linked to wellbeing and are low-scoring). This may be due to high variation within the small sample size, which can reduce the clarity of statistical relationships and obscure clear priority needs. However, the factors below received the lowest agreement scores, indicating areas with potential for meaningful improvement.

**3 in 5**
Didn't agree they were able to **emotionally accept** their child's cancer diagnosis (59%)

**2 in 5**
**Felt helpless** at times (43%)

**3 in 5**
Didn't agree they had the opportunity to maintain their physical wellness (58%)

For more information, see the *Child Cancer Foundation 2024–25 Social Impact Report.*

# Factsheet: Strengths and What Helps Most for Families Off Treatment

Those in the off-treatment measurement group were families of children who had previously been diagnosed with cancer, but had already undergone treatment and were in remission. Off-treatment families reported a wellbeing score of 5.86, which was the highest score out of measurement groups and above the wellbeing score for the same group in 2023-2024 (5.41). The high score of these families may be indicative of the fact that their child's cancer treatment was effective and their child was no longer requiring medical care for their diagnosis at time of measurement.

## Off-treatment families had recently felt joy, time to look after their physical wellness, and felt financially secure

**94%**
Recently felt they had **moments of joy**

**84%**
Felt they had the opportunity to maintain their **physical wellness**

**83%**
Felt they could understand and **manage their financial situation**

**79%**
Agreed CCF helped them **manage the overwhelming amount of info** on their child's diagnosis

## Support with anxiety and late effects most helpful for off-treatment families

**2 in 3**
Recently felt **anxious**
(65%)

**2 in 5**
Reported late effects
(43%)

As the families of children who were no longer being treated for cancer, it is unsurprising that off-treatment families reported the highest wellbeing scores across measurement groups. This was reflected in off-treatment families' strengths: feeling joy, having the opportunity to maintain their physical wellness and manage their financial situation, and have enough income. However, along with these strengths, the majority of families had recently felt anxious (65%), and 43% of off-treatment families reported late effects; problems caused by cancer treatment months or years after treatment (n=21). These included hearing loss, loss of an eye, nausea, tremors, fatigue, other physical challenges, mental health challenges, and weight challenges. Anxiety and late effects continue to be areas where further focus and support could greatly uplift families coming off treatment.

For more information, see the *Child Cancer Foundation 2024–25 Social Impact Report.*

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# Factsheet: Strengths and What Helps Most for Bereaved Families

Those in the bereaved families measurement group were families who sadly lost a child to cancer. The number of respondents for this group are generally smaller than other groups year on year, with seven respondents in this group during the 2024-2025 measurement period. These families had a wellbeing score of 5.23, slightly higher than the previous measurement period (4.94), and higher than the new families and on-treatment families measurement groups (4.94 and 4.67 respectively).

## Bereaved families reported being able to find moments of joy in life and spend quality time with loved ones

**100%**
Recently felt moments of **joy**

**100%**
Felt they spent **quality time** with people they cared about

**100%**
Felt they had **someone who would listen** when they needed to talk about worries and problems

**100%**
Agreed CCF helped them learn ways to **manage their emotions**

## Support for loneliness and anxiety, plus information on bereavement support services may benefit bereaved families

**1 in 2**
Felt **lonely** (50%)

**3 in 4**
Recently felt **anxious** (75%)

**1 in 3**
Didn't know of **grief and bereavement support services** they could use if they wanted to (33%)

Despite the challenges of bereavement, families are showing strong emotional and practical resilience. The consistent experiences of joy, connection, support, and day-to-day functioning suggest that families are drawing on effective coping strategies, likely strengthened by strong and healthy relationships and support networks.

Although the small sample size limited the use of statistical analysis to identify priority needs, the factors below received the lowest scores from bereaved families, indicating areas with potential for meaningful improvement. These findings highlight opportunities to strengthen emotional support and increase awareness of available resources for bereaved families, which may help families feel more connected and supported during this difficult time.

For more information, see the *Child Cancer Foundation 2024–25 Social Impact Report.*