



Child Cancer Foundation Social Impact Report

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

June 2022

Prepared by



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Acknowledgement of Country

Huber Social acknowledges the Traditional Owners and Custodians of Country throughout Australia and their continuing connection to land, waters and community. We pay our respects to the people, the cultures and the Elders past, present and future.

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Supporting Families Along their **Journey with Cancer**

On receiving the news that your child has cancer a parent's whole world view completely changes. In New Zealand, this happens to about three families per week. Navigating the medical system through such a difficult journey can be challenging - physically, emotionally, and financially. Upon return, families may struggle to communicate their experience and find a community that understands and can support them as they adjust to their 'new normal'.

Child Cancer Foundation (CCF) believes no family should be left to undertake this alone. As one of the leading childhood cancer support providers in New Zealand, CCF "focuses on whānau, not the cancer." They walk with families on their cancer journey and provide them with the bespoke help they need, whether it be a place to stay during treatment, financial and emotional support, access to a network of parents sharing in the same struggles, or a listening ear.

To strengthen the empirical evidence of its impact, CCF partnered with Huber Social in 2020 to establish a measurement system that can demonstrate (measure) the social impact of CCF and identify opportunities to maximise that impact.

An initial pilot was conducted in 2020 to confirm the best approach to measurement. Lessons learned were applied to this year's measurement process, tools and analysis. The measurement plan and surveys were reviewed and refined from August - September 2021, with data collection beginning in October 2021.

It is important to note that the 2021-2022 measurement was conducted during the COVID-19 pandemic. Many CCF services were impacted by the restrictions placed on domestic travel, hospital access and social



Every child and their family deserve to be well, maintain hope and continue to dream.

distancing measures. This limited access may likely be reflected in the results with respect to CCF service access, utilization and perceived impact by families.

Results of this year's measurement have built on the pilot's initial findings, and aim to support CCF by offering a resource that can inform internal decision making, strengthen support from donors and identify opportunities to collaborate with others, as well as satisfy requirements of the new accounting standards. With routine measurement and a growing evidence base, CCF can have greater confidence in its approach to supporting families and whānau through their child's cancer journey and the positive impact CCF has on their wellbeing.



Why Measure **Social Impact?**

Huber Social was engaged to measure the social impact of CCF to demonstrate the organisation's overall impact and identify opportunities to maximise effectiveness and better allocate resources.

1. Measure

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

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

2. Maximise

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

This approach identifies opportunities to refine CCF services (if required) and utilisation of resources to maximise the organisation's impact on client 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, programs are having a positive impact. To measure social impact, Huber Social therefore measures a shift in overall wellbeing and the specific program 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.



About Child Cancer Foundation

CCF stands shoulder-to-shoulder with families who have a child facing cancer. They are there to guide them every step of the way, both now and in the future.

CCF aims to support families through three specific goals:

Goal 1: Provide practical support to families at all stages of the cancer journey

Outside of medical treatment, CCF recognises the best way to support children with cancer is to provide wrap around support services to them and their families, with a focus on the parents as their primary carers. They offer and co-ordinate individualised support across 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.

FSCs support the whole family, helping them to identify and draw on their strengths, focus on what they can do, make memories and maintain hope. They coordinate the individual support and offer hope and comfort, helping parents take the time they need for themselves, normalising their feelings, and providing 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, but certainly not limited to; 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.

Goal 2: Fund research to improve care

CCF supports ground-breaking childhood cancer research through multiple streams, including the Precision Paediatric Cancer Project (PPCP), the Challenge Research Fund, and involvement in studies with other sector leaders such as the National Child Cancer Network, Cure Kids and the Lindsay Foundation.

Goal 3: Provide peer-to-peer support for families

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

The findings of this report will provide evidence specifically for how CCF fulfils Goals 1 and 3. While this report does not focus on the outcomes of Goal 2, the impact of CCF's investment in paediatric cancer research can be found on their website and across other publications.



The Child Cancer Foundation **Impact Thesis**

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

1. Impact

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



2. Outcomes

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

Capabilities

- Community connection
- Resilience
- Life skills
- Holistic wellness

Opportunities:

- Relationships
- Social structures
- Resources
- Self-development



3. Outputs

CCF delivers the following outputs:

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



4. Activities

These outputs are achieved with the following activities:

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



5. Resources

The above impact requires the following inputs:

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



Measurement Approach

Design

To assess the impact of CCF services, Huber Social set out to measure the overall wellbeing (impact) and levels of capability and access to opportunities (outcomes) of families enrolled with the organisation. To understand which outcomes were most critical for inclusion in this evaluation, a co-design workshop was first held with key stakeholders from across CCF. Following the pilot measurement, revisions were made to the measurement approach and tools based on lessons learned from the previous experience.

Measurement Tools

In both years of measurement, 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.

Ethical Review

The CCF measurement project was submitted to the Huber Social Ethical Review Board for ethical assessment (Committee No. EC00473). It was granted approval on 30 September 2021.

Survey Distribution and Data Collection

Online survey links were distributed by CCF via email from 1 October 2021 to 30 April 2022. Surveys were sent to families on a monthly basis as they reached key timings in their

cancer journeys:

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

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

This staggered approach differs from the pilot measurement, which had one survey distribution (July 2020) to all current CCF clients. The justification for this new approach was to reduce the number of clients receiving the survey who have had no recent engagement with CCF.

Sample Size and Response Rate

In total, 50 out of 326 surveys distributed were completed by CCF families, for a response rate of 15%. This includes 47 out of 310 survey sent to families with a recent, current or former diagnosis of cancer (in correspondence with the aforementioned timings) (14% response rate) and 3 out of 16 surveys sent to bereaved families (19% response rate).

While low, these response rates are comparable to those of other studies within the paediatric cancer population*, and mark an increase from the previous year (9% response rate).

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

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

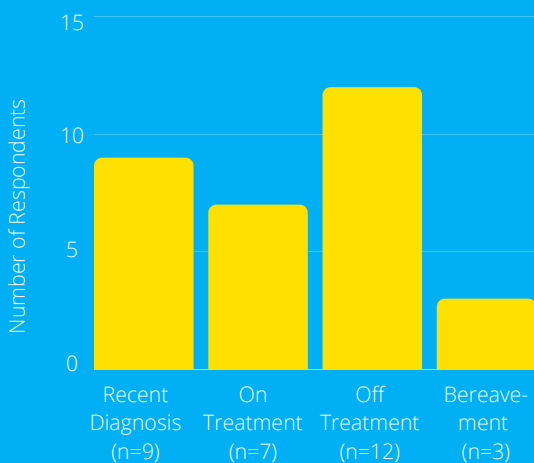


Measurement Groups

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

- **Recent diagnosis (baseline):** 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



CCF Families by Journey Stage



Survey Respondent Demographics

The following offers some key insights into the demographic make up of CCF's Wellbeing Survey respondents. The majority (58%) of responses are from families with children still undergoing treatment, and nearly all (98%) are or were parents (rather than guardians) to a child with a cancer diagnosis.

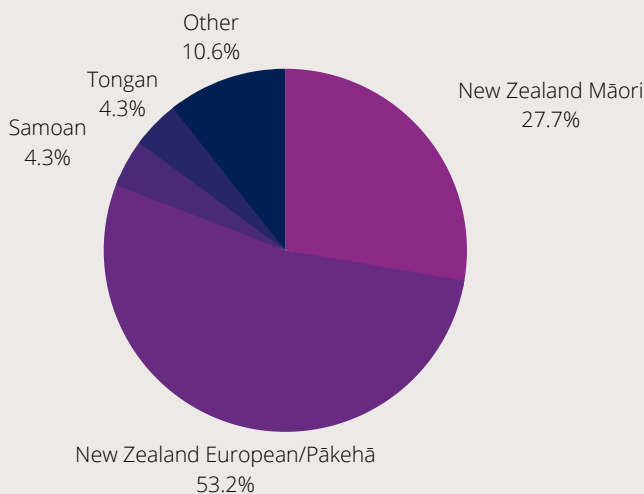
Location

The respondents sample is largely representative of all CCF families from June 2021- May 2022, with the largest difference in Tauranga (7% overrepresentation). There was no representation from CCF families in Lakes, Tairawhiti or Taranaki.

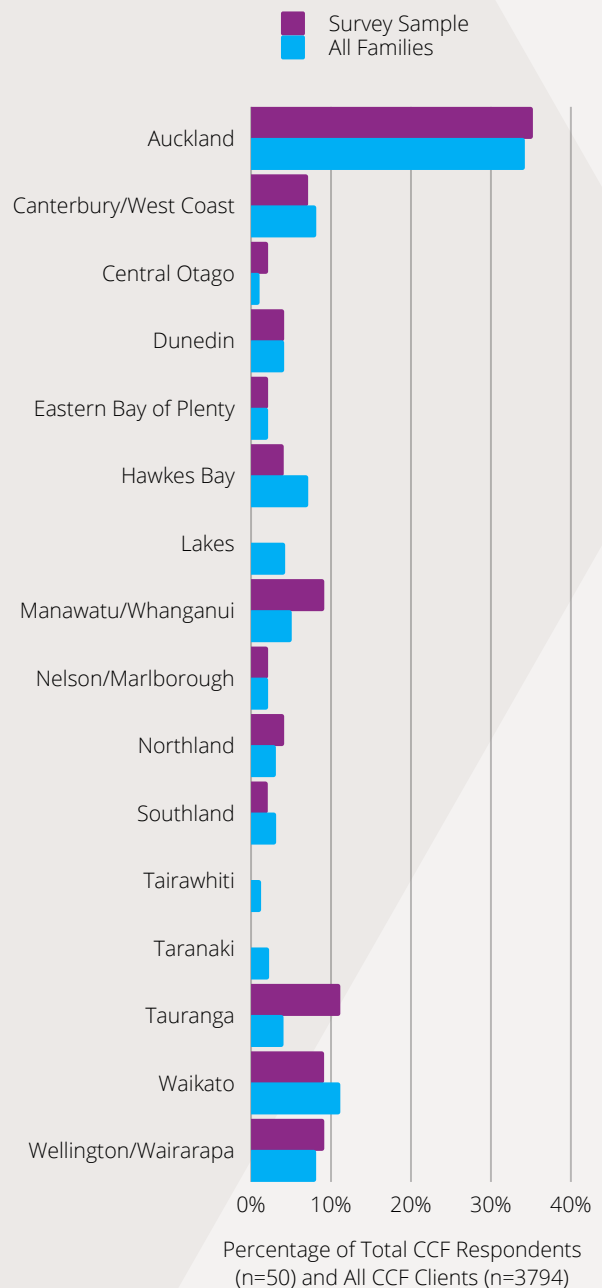
Ethnicity or Heritage

Most respondents identify as New Zealand European/Pākehā, with over one-quarter identifying as New Zealand Māori. Other ethnicities and heritages represented include Chinese and European.

All Responses, by Ethnicity or Heritage



All Responses, by Location





Key Findings

The following are key high-level findings that provide evidence supporting Goals 1 and 3. The following sections explore these findings and additional data to support the impact of CCF's work.

1. CCF supports new families to access key services

For new families, access to key resources and utilization of more support services is associated with higher wellbeing. 89% of new families believe that CCF helps them access the services they need.

2. CCF supports on treatment families to emotionally accept their child's diagnosis

For families on treatment, emotional acceptance of their child's diagnosis is associated with higher wellbeing. 50% of on treatment families believe that CCF supports them to emotionally accept their child's diagnosis

3. CCF supports off treatment families to access supportive relationships

Off treatment families have significantly more supportive relationships (18%) compared to new families. 100% of families also believe CCF has helped them to develop and maintain these relationships.

4. CCF supports families to manage medical information

For families at any stage, feeling overwhelmed by diagnostic information is associated with lower wellbeing. 95% of families believe that CCF helps them feel less overwhelmed by the amount of medical information they receive.





The **Impact** of Child Cancer Foundation

The remainder of the report presents the overall impact of CCF, and speaks to the organisation's specific goals. It is divided into three sections:

- Overall Impact: In terms of families' overall wellbeing and satisfaction with their CCF experience.
- Goal 1: Providing families with practical support at all stages through the cancer journey
- Goal 3: Provide peer-to-peer support for families

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.





The Overall Wellbeing of Child Cancer Foundation Families

The average overall wellbeing of CCF families is 4.52 out of 7. This level indicates that CCF families are just slightly satisfied with their life and current conditions. Overall wellbeing was measured using the Satisfaction with Life Scale.*

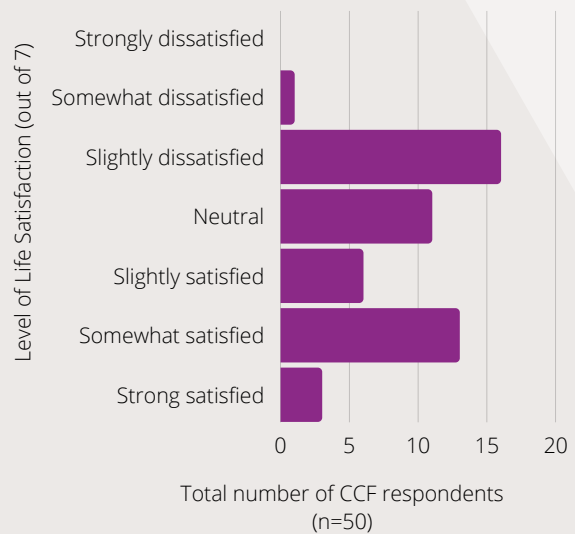
Scores had a wide distribution, ranging from 2.2 to 7. While a bell-shaped distribution is more typical, the unevenness may be due in part to the distribution of families across the various cancer journey stages and the impact each stage can have on wellbeing. For example, the majority of families who are slightly dissatisfied with life are also those who have received a recent cancer diagnosis within the past 3-6 months.

What is encouraging to note is that there are no families who have reported saying they are strongly dissatisfied with their life at present. This suggests that no matter what challenges a childhood cancer diagnosis may pose, CCF families are still able to maintain at least some aspects of their wellbeing.

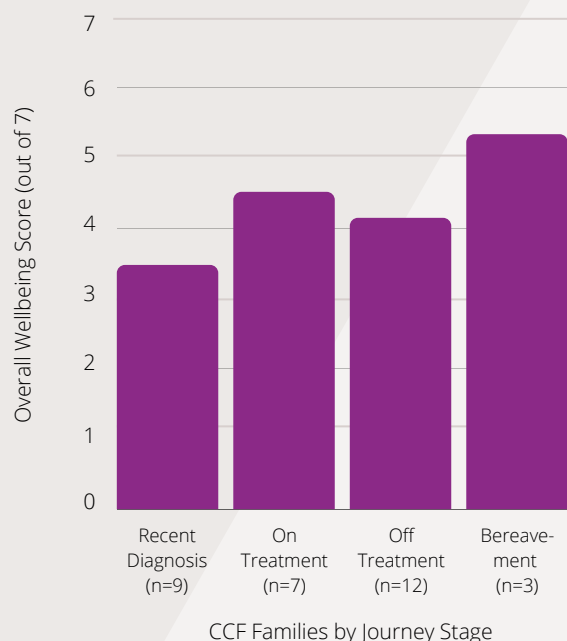
Wellbeing by cancer journey stage follows an anticipated pattern. Families with a recent diagnosis find themselves at the lowest wellbeing point; this increases as children successfully proceed through their treatment course and transition to post-treatment life. **Compared to families with a recent diagnosis, families who have been on treatment for approximately one year had 30% higher wellbeing on average.**

Encouragingly, for those families who have lost a child within the past 18 months are feeling slightly satisfied with their life on average.^ However, given the small sample size of this measurement these findings should only be considered indicative at this point, and not necessarily generalised to all bereaved CCF families.

Distribution of CCF Families' Overall Wellbeing Scores



Average Overall Wellbeing by Measurement Group



*In 2021-2022, the items used in the Satisfaction with Life Scale were reverse worded; therefore, results are not comparable to pilot scores.
^Bereaved families scored an average 5.33 out of 7.

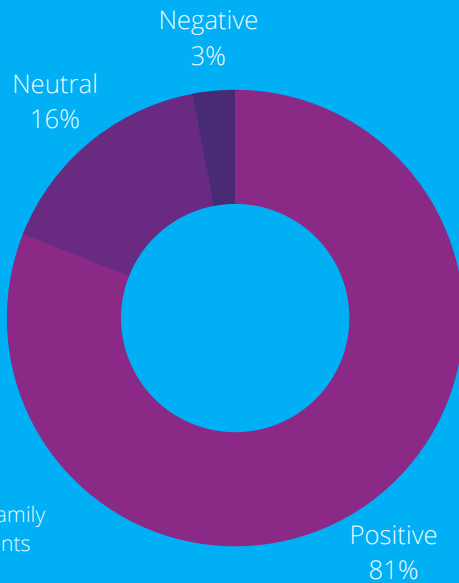


Overall Satisfaction with Child Cancer Foundation

When asked about their overall experience with Child Cancer Foundation, four out of five families said they have had a positive experience with the organisation.

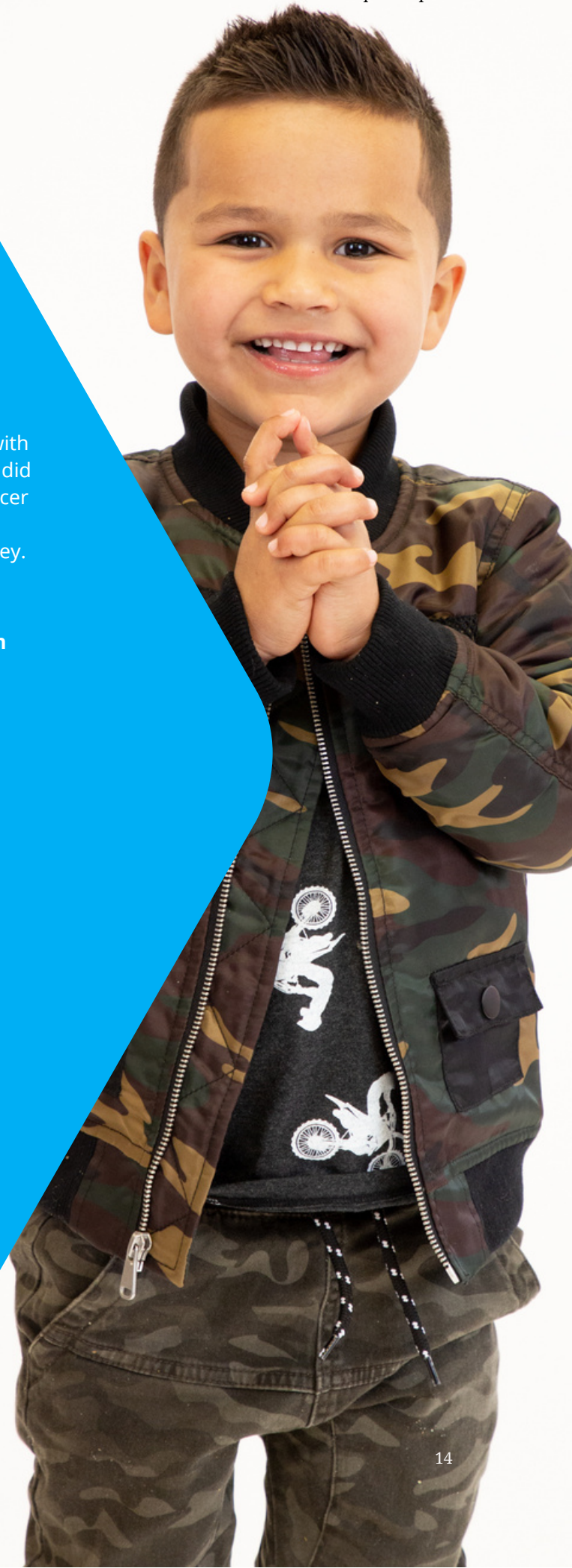
Families were asked to rate their overall experience with CCF (positive, neutral, negative). Experience with CCF did not vary significantly by demographic factors nor cancer journey stage, indicating that CCF offers a positive experience to all families at every stage of their journey.

Overall Satisfaction with Child Cancer Foundation



Feedback from CCF families who reported having a negative or neutral experience included:

- Being referred to CCF services too late in journey;
- Not receiving the type of financial support requested; and
- Feeling overwhelmed by the amount of contact received from CCF.





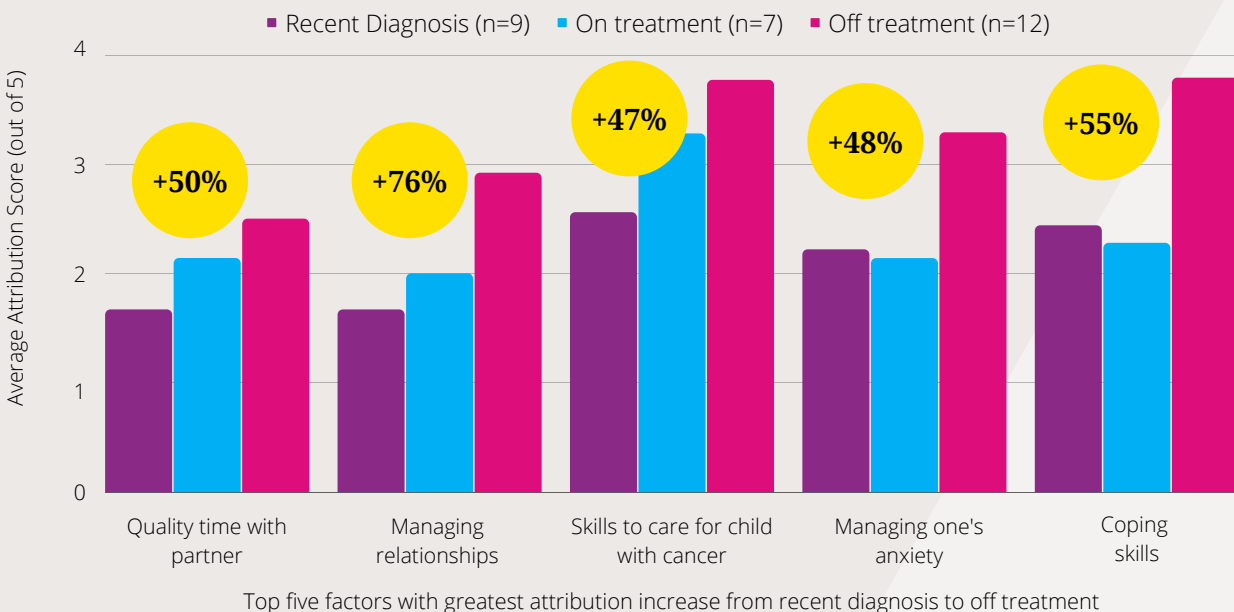
Child Cancer Foundation Service Impact Builds Over Time

As part of the wellbeing assessment, families were asked to evaluate 'how much' they feel that CCF has supported them across key program outcomes*. This includes support in accessing services and resources as well as support in strengthening personal capabilities such as their emotional and mental wellness, the quality of their personal relationships, and resilience skills. By understanding how much families believe that CCF is responsible for the current state of their wellbeing needs (attribution), CCF can strengthen its understanding of which services have the greatest impact on the needs of their families, and which needs families may be addressing independent from the organisation.

On average, families feel that CCF is responsible for supporting about 50% of their total wellbeing needs. The remaining 50% may come from other support networks, personal relationships, families' own efforts in accessing resources, or their own pre-existing capabilities. At a factor-level, attribution ranged from 36% (families are adaptable to change) to 66% (families have access to supportive relationships).

As the graph below demonstrates, perceived support from CCF increases over time as families progress from one stage to the next. Compared to families with a recent diagnosis ('new families'), families who have completed treatment within the past year ('off treatment') attribute their current wellbeing needs status 25% more on average to CCF support. The following graph depicts the top five factor with greatest CCF attribution score increases from recent diagnosis to off treatment. ^ This demonstrates that on average, the longer families are with CCF the greater they attribute the impact of CCF services to their wellbeing needs.

Distribution of CCF Families' Overall Wellbeing Scores



*For each program outcome measured, families were asked 'how much has CCF supported you with this?' Responses were rated on a 5-point unipolar scale from 'not at all' (1) to 'completely' (5).
^ Bereaved families excluded from this analysis due to their small sample size



Goal 1: Provide practical support to families at all stages of their cancer journey

The following section examines how CCF has worked towards achieving Goal 1 for the 2021-2022 reporting period. To understand the impact of providing practical support to all families, the following outcomes metrics will be assessed:

- **Access and utilisation of support services:** Do all families have access to CCF services? How are those services being used? Are there any services they need but do not have access to?
- **Life skills:** In addition to materials needs, do families have the knowledge and skills for managing a childhood cancer diagnosis?
- **Holistic wellness and resilience:** In addition to material needs, are families' holistic wellness needs being met? Are they resilient?





Use of Child Cancer Foundation Services

CCF prides itself on offering a wide range of services to meet any and all needs of its families. To measure the impact of these services on overall wellbeing, it is important to first understand how families are interacting with CCF services.

It should be reiterated that during this year's measurement, service delivery was severely impacted by the COVID-19 pandemic. Families had restricted access to certain services such as travel support and Family Places or other care homes; and some services changed their delivery method, such as FSC communication and counselling services moving online.

All CCF Services

When asked about all CCF services ever used, the **majority of families said they had connected with an FSC (81%)**. Over one-third of families have used short-term financial support services from CCF (38%), and one-fifth have used CCF wellbeing information (21%).

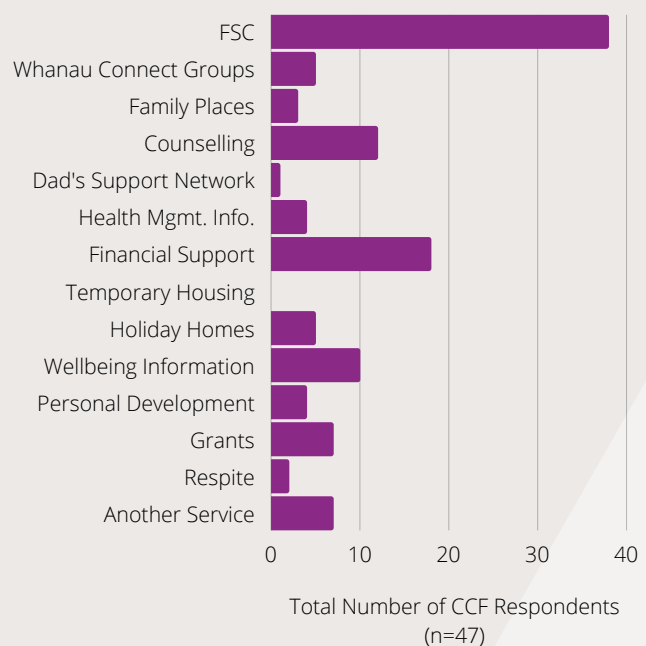
Quality of Resources

Families who indicated that they were living away from home during treatment were asked to rate the quality of CCF resources available to them in their temporary housing situation. On average, respondents said that toiletries were of high quality, and hospital meals and entertainment were of average quality. All families reported having access to the right technology to stay in touch with family members and friends

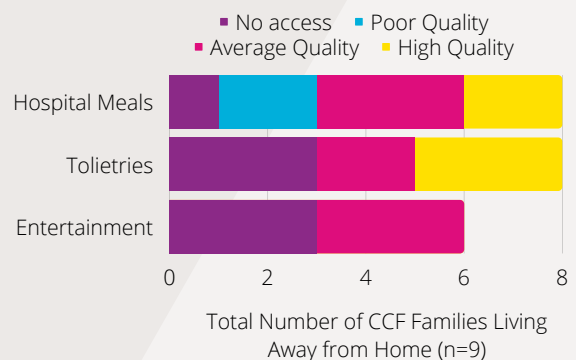
Overall Access

Of all respondents, **only 54% of families report being able to access the services they need**. However, when asked what additional services are needed none were specified. Additionally, only 4% of respondents said they had the opportunity to attend a CCF Wellbeing Workshop. These results may be indicative of limited access to services due to the pandemic, and may warrant follow-up research.

Types of CCF Services Used



Quality of Resources When Living Away from Home





Child Cancer Foundation Families Appreciate their Family Support Coordinators

As FSC's are the most utilised CCF service, families across all stages of their cancer journey had expressions of gratitude to share about their FSC:

- "Our FSC has been a huge comfort through our journey and was always happy to listen to me vent, and listen to our son talk about random things."
- "Our FSC has been lovely. She's helped our family feel loved especially when we were away from our actual home and family. She had provided all the information on the services that were available to us and ensured we made the most of it. She encouraged us to make sure we get through this journey in the right head space."
- "Child Cancer Foundation is such an awesome service. My FSC always just listened to me talk, and never once made me feel insecure... She taught me strategies in overcoming scenarios that were happening in my life."
- "Our FSC is really positive and really kind not overwhelming or in my face but just what I need I think. I don't really know what to do but having a chat with someone is nice every now and again I also like the fast response I get when I'm feeling weak."



Access to Counselling Services

Receiving a childhood cancer diagnosis is a traumatic shock to all family members. Families may need additional support to emotionally recover from that experience, both in the immediate and long-term.

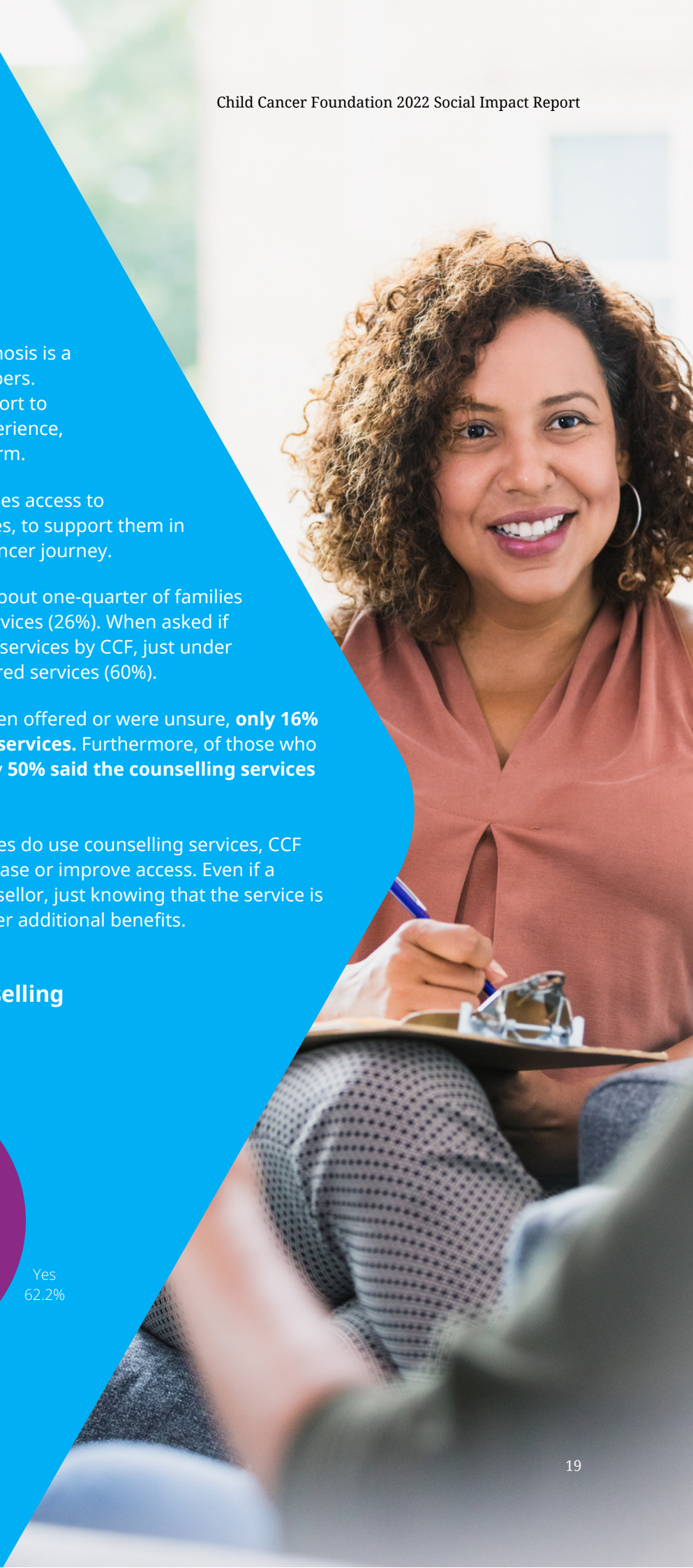
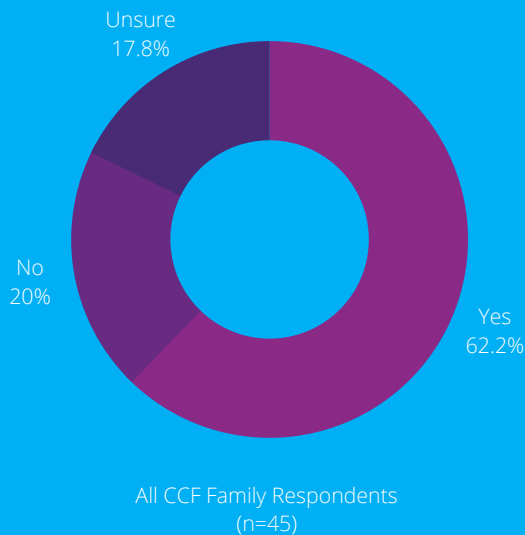
The CCF Counselling Project provides access to counselling services for CCF families, to support them in processing and healing on their cancer journey.

In the 2021-22 Wellbeing survey, about one-quarter of families reported using CCF counselling services (26%). When asked if they had been offered counselling services by CCF, just under two-thirds said they had been offered services (60%).

However, of those who had not been offered or were unsure, **only 16% knew how to access counselling services**. Furthermore, of those who had used counselling services, **only 50% said the counselling services met their needs**.

Given that more than half of families do use counselling services, CCF may wish to consider ways to increase or improve access. Even if a family does not wish to see a counsellor, just knowing that the service is there and how to access it may offer additional benefits.

CCF Families Offered Counselling Services





Access to Key Support Services

Access to support services is vital to all families experiencing and recovering from childhood cancer, but particularly for those who have recently received a life-changing diagnosis and are in need of additional care.

Analysis demonstrates that specifically for new families, those who feel that they have greater access to key support services are more likely to also have higher overall wellbeing.* **This suggests that access to key services is more critical to overall wellbeing at the beginning of a family's journey with cancer as compared to families who are further along in treatment and recovery.**

On average, new CCF families reported feeling slightly confident in their ability to access CCF support services (5.11 out of 7). Families one year into their cancer treatment ('on treatment') and those off treatment reported

similarly, with no significant difference in levels of access detected.

However, for new families it's not just about having access to these services; actually using the support services offered by CCF was also associated with higher wellbeing among new families.* In 2021-2022, the most utilised service by new families was connecting with their FSC (89% of new families). Beyond providing them with the attention and care they need, 100% of new families also believe that their FSC treats them with respect.

Additional services utilised by new families include short-term financial support, respite care, and other types of services such as vouchers (22% of new families). On average, new families were found to use the same quantity of CCF services as other families.

"Child Cancer Foundation has helped so much. Beads of Courage to help remember her story, petrol so we were able to attend appointments and having someone to talk to who understands what we are going through."

- CCF Wellbeing Survey Respondent

**See Appendix for statistical analysis results.*





Child Cancer Foundation Supports Families to **Access Key Services**

Most significantly, CCF support was found to be positively correlated with utilisation of CCF services*.

These findings indicate that the more support CCF offers to new families, the more likely families are to have access to and utilise key services critical to maintaining and improving their overall wellbeing.

On average, 9 out of 10 new families believe that the support CCF offers has helped them at least a little bit in accessing the support services they need, indicating that CCF is successful in supporting new families where it will have the greatest impact on their wellbeing.

**See Appendix for statistical analysis results.*





Daily Life Skills

Providing practical support to families with childhood cancer includes enabling them with the skills and knowledge to navigate any short and long-term challenges in life, such as the ability to care for their sick child, understand and manage their financial situation, and process their emotions in a healthy manner.

Of all the upskilling that CCF provides to families, being able to **manage their child's medical information without feeling overwhelmed** was identified as being most critical to maintaining a family's overall wellbeing, regardless of their cancer stage.*

Feeling overwhelmed by the amount of information received regarding their child's diagnosis was negatively associated with overall wellbeing across all families.

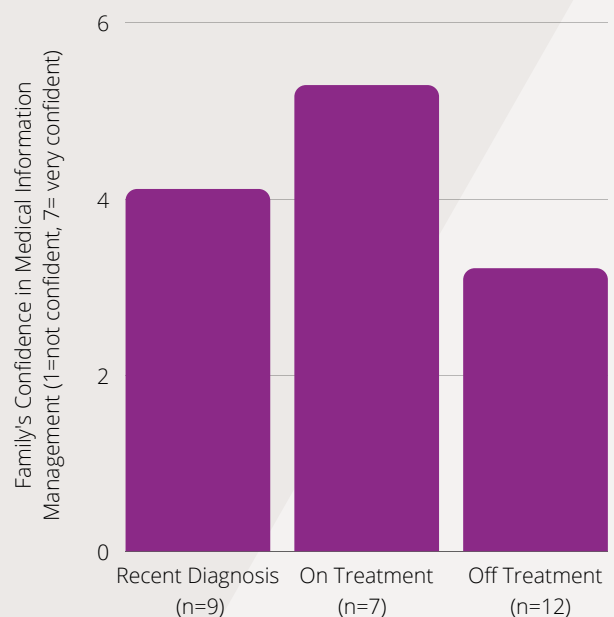
On average, the more a family feels overwhelmed by the amount of information they receive about their child's diagnosis, the lower their wellbeing is likely to be.

While on treatment families feel the most confident, off treatment families feel 39% more overwhelmed by the information they receive regarding management of their child's cancer diagnosis.

Encouragingly, **95% of all family respondents believe that CCF supports them in understanding and processing information received about their child's medical diagnosis.** While CCF support was not found to influence families' information management skills, continued data collection and larger sample sizes will strengthen these results.



Family's Confidence in Being Able to Manage the Amount of Medical Information Received About Their Child's Cancer Diagnosis



CCF Families by Journey Stage

*See Appendix for statistical analysis results.



How CCF Helps Families Manage Their Child's Cancer Diagnosis

In addition to their services, families mentioned additional ways that CCF helps them to manage their child's diagnosis, including:

- Encouragement to ask for and accept help
- Ensuring food safety
- FSCs being an available person to talk (or vent) to
- Information about child's diagnosis and treatment
- Information about other CCF services and programs, including Beads of Courage, financial support, groceries, and counselling services
- Wellbeing newsletters

"I've had phone calls with an empathetic support worker, I've had a couple of frozen meals in hospital which have been much appreciated. I have also been sent some petrol vouchers, and a disability parking permit is being arranged by CCF. All great practical supports that do actually impact our daily living."

- CCF Wellbeing Survey Respondent



Holistic Wellness and Resilience

Holistic wellness - physical, mental, spiritual - and resilience are two key strengths that all families must achieve and maintain to successfully navigate their childhood cancer journey. CCF aims to support families' wellness and resilience through support of their FSC as well as access to health and wellness services such as counselling.

Of all factors measured, the following three were found to be important to overall wellbeing:



Hope

Hope was found to have a strong positive relationship with overall wellbeing of all families, and particularly for those off-treatment or who had lost their child.

After one year into treatment, families feel on average over 50% more hopeful than when they were diagnosed. However, this decreases slightly once treatment is complete (23%). Inspiringly, bereaved families were found to be the most hopeful of all.

Over two-thirds of all families believe that CCF supports them to have hope.



Anger

Anger was found to be negatively correlated with high wellbeing for all families, particularly for off-treatment families and bereaved families. This means that the more frequently a family feels angry, the lower their wellbeing is likely to be.

As families progress through treatment, they are also likely to feel less angry than when they first received their diagnosis.

As with hope, over two-thirds of all families believe that CCF supports them to manage their anger.



Resilience

Resilience - in particular, recovery from setbacks - was found to have a positive relationship with wellbeing, particularly for on-treatment families.

On-treatment families are mildly confident in their ability to recover from setbacks.

One-third of families on treatment believe that CCF supports them with this type of resilience.

These findings offer insight into those wellness and resilience factors most important to the wellbeing all CCF families, and clear guidance for where CCF should direct its efforts in meeting families' holistic wellness needs. While these needs were not found to be influenced by CCF support in this year's analysis, further data collection and larger sample sizes may reveal new findings.



Child Cancer Foundation Helps Families Emotionally Accept their Child's Diagnosis

Being able to emotionally accept a child's diagnosis is a significant milestone in a family's cancer journey, and is often one that cannot be reached alone.

For on treatment families, being able to emotionally accept their child's diagnosis was associated with higher wellbeing.* This means that **the more an on treatment family can accept their child's diagnosis, the more likely they are to have higher wellbeing.**

On average, on treatment families believe they can accept their child's diagnosis, but only slightly.^ This level of acceptance does not differ from other families at different stages of their cancer journey.

However, this is an area where CCF support was found to likely make a difference. **The more CCF supports families with this process, the more likely on treatment families are to feel confident in their ability to emotionally accept their child's diagnosis.** This, in turn, supports their wellbeing.

In this year's measurement, 50% of on treatment families believe that CCF supports them with accepting their child's diagnosis. Greater perceived support is more likely to lead to greater acceptance, so this is an area of service delivery that CCF will want to continue to focus on in future programming.

*See Appendix for statistical analysis results.

^On treatment families scored 5 out of 7, indicating that they slightly agree that they can emotionally accept their child's cancer diagnosis.





How Families Remain Resilient

In addition to CCF services, families mentioned additional ways they remain resilient throughout their child's cancer journey, including:

- Being able to relate to other families' successful journeys
- Family, friends, whānau – their 'village'
- Faith
- Keeping a sense of normality, such as continuing to work, daily life tasks, gardening, etc.
- Knowing that support systems are in place
- Maintaining a positive mindset

"The impact [of Child Cancer Foundation] has been immense. I am here, and my family are stronger together."

- CCF Wellbeing Survey Respondent



Goal 3: Provide peer-to-peer support for families

The following section examines how CCF has worked towards achieving Goal 3 for the 2021-2022 reporting period. To understand the impact of providing peer-to-peer support to all families, the following outcomes metrics will be assessed:

- **Access to Peers:** Do all CCF families have access to peer support? How and where are CCF connecting with each other?
- **Healthy Relationships:** Do CCF families have the knowledge, skills and access to support services to nurture their personal relationships, beyond those of CCF?
- **Community Connections:** Do CCF families have access to communities that offer care and comfort, both within CCF and beyond?





How Child Cancer Foundation Families Connect

Research has demonstrated the importance of families experiencing childhood cancer to be able to connect with others who have shared their experience. CCF prioritises facilitation of these connections as one of its principle methods for supporting its families. To measure the impact of its peer-to-peer support, it is important to first understand how CCF families are connecting with each other.

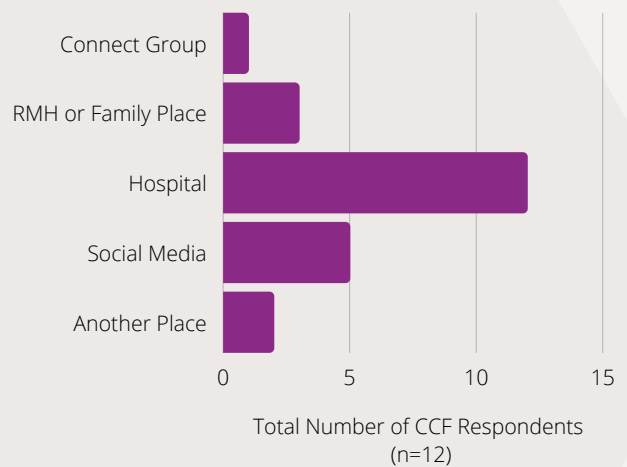
Where CCF Connections

When completing the 2021-22 Wellbeing Survey, about one quarter of families (26%) indicated where they're connecting with others. **100% of families indicated that they connected with other families at the hospital where their children were receiving treatment.** Just under half of families indicated that they were connecting with others via social media (42%). It should be reiterated that due to the pandemic, many families were unable to access communal places of respite such as Ronald McDonald House (RMH) or Family Place; thus, the low response rate for connection places may in part be due to the challenges CCF families and New Zealand as a country were facing at this time.

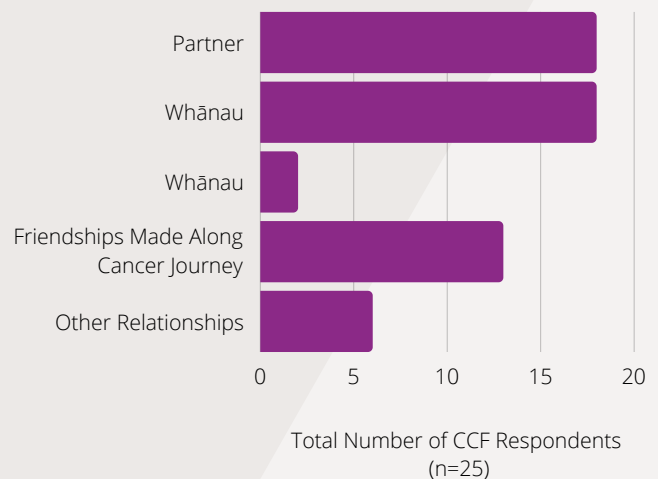
Personal Relationships

In addition to connections facilitated by CCF, the Wellbeing Survey asked families about their supportive personal relationships. **72% of respondents cited their partner, family or whānau as a source of support.** 52% indicated friendships created during their child's cancer journey, and 24% indicated other relationships including friends, care staff for their child, and work colleagues. While only 8% stated that friendships made through their local Whānau Connect Group were a source of support, this may be due to the limited Connect Group gathering that were happening during this measurement time, and which were conducted virtually if at all.

Places Where CCF Families Connect



Supportive Personal Relationships





Child Cancer Foundation Provides **Supportive Relationships**

Families who are currently or have recently experienced a childhood cancer diagnosis often rely on the support of family, whānau and friends, for anything from emotional support to help in doing everyday tasks.

Ensuring that everyone has access to a social network is one way that CCF can support families. When asked if families have someone in their life to help and support them, 82% responded in the affirmative.

Off treatment families were 24% more likely to have someone in their life compared to families with a recent diagnosis, and 100% of off treatment families stated that they could attribute that at least a little bit to CCF services.

On average, families attributed CCF help in creating and maintaining these supportive relationships more than any other outcome measured, indicating that this is where families believe CCF services - such as access to their FSC - have the greatest impact.

While access to supportive relationships is not significantly correlated with wellbeing, this is undoubtedly still an area where CCF will want to continue directing resources, particularly to fill any gaps that families may have in their social support networks.





Quality Relationships

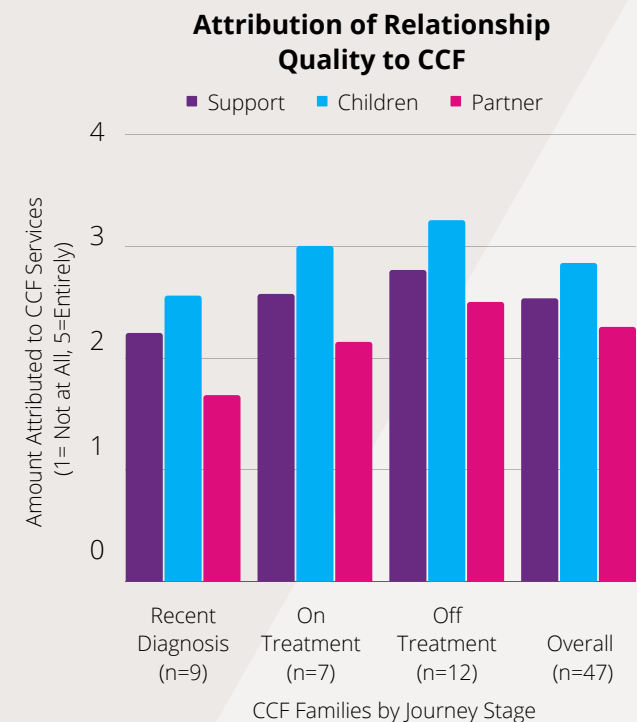
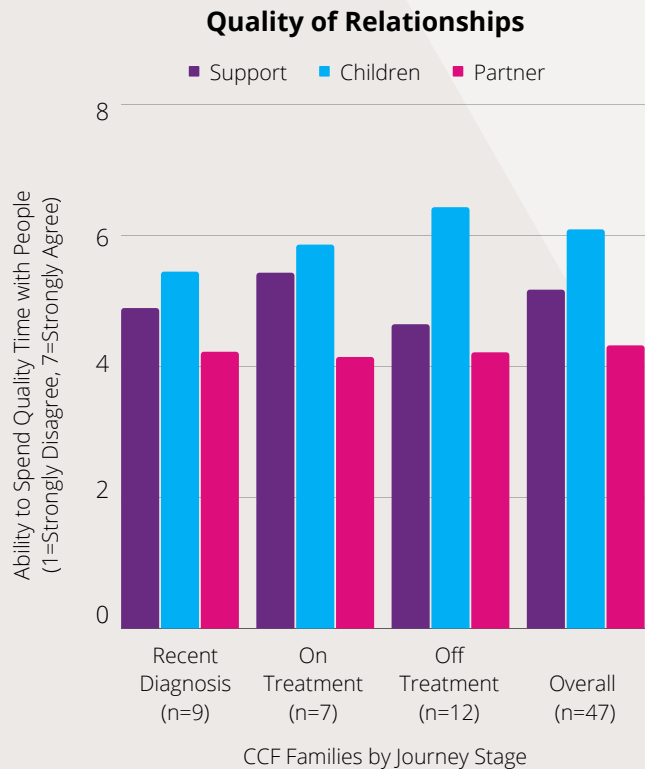
Beyond helping families identify and access supportive relationships, CCF supports families by enabling them to spend more quality time with the people that matter most to them.

To understand how CCF supports families to maintain healthy relationships, the quality of families' relationships were assessed, specifically with respect to the perceived amount of quality time families spend with their partner, children, and other support people in their network. The amount CCF supports families to spend quality time with each of these groups was also measured.

Results reveal that on average, CCF families are able to spend 30% more time with their children and support networks compared to their partner. This difference increases to 36% for on treatment and 31% for off treatment families.

In terms of attribution of CCF support, on average CCF families feel that CCF supports them slightly to manage their personal relationships*. Attribution of CCF support is largely the same across all types of relationships and cancer stages, with the exception of families with a recent diagnosis. New families believe that CCF support helps them 43% more to spend time with their support network and children than with their partners.

*Average overall attribution of CCF services across all relationship types is 2.55 out of 5.





New Families Struggle to Nurture Partner Relationships

Families across all stages of their child's cancer journey do not get to spend enough time with their partner and feel that their relationship is struggling due to the pressures from their child's cancer diagnosis.*

Families with a recent diagnosis feel this more acutely, and also attribute less support from CCF towards improving their relationship with their partner.^

COVID-19 limited the amount of partner support CCF could provide to families and limited access to hospitals was a likely stressor during this measurement period, which may explain the lower levels of attribution.

While neither factors were found to be directly correlated with overall wellbeing, new families who report feeling that CCF has helped them more with managing their partner relationships are more likely to have higher wellbeing, indicating that support here is more likely to have a positive impact on wellbeing as compared to other service areas.

**Average quality time spent with partner scored 4.22 out of 7 (neither agree nor disagree that they are able to spend quality time with their partner). Average score of relationship struggles due to cancer diagnosis scored 3.31 out of 7 (slightly agree that it is struggling).*

^Less than half (44%) of new families believe that CCF helps them at least a little bit to spend more time with their partner, and only 1/3 of new families believe that CCF helps them at least a little bit to manage their relationship struggles due to their child's diagnosis.





Community Connections

"Child Cancer Foundation were always there for us. I have met some amazing people who I will know for life."

- CCF Wellbeing Survey Respondent

Enabling families to connect with others experiencing childhood cancer has been identified as a key area of support that organisations like CCF can and should prioritise.*

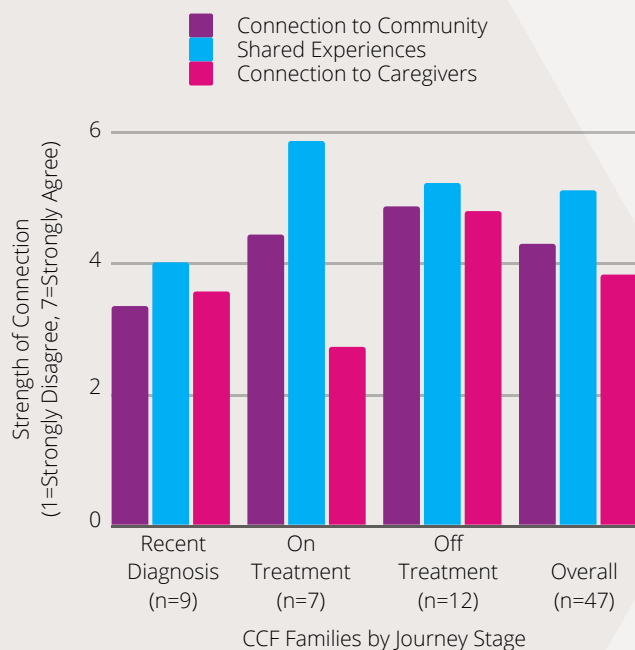
To understand how CCF creates community connections with peers, three connection factors were measured: (1), families' sense of connection to a community, (2) families' sense of connection to others with shared experiences, and (3) families' sense of connection to other caregivers of children with a cancer diagnosis.

Analysis found that in general, off treatment families feel the most consistently connected across all three factors. Compared to families with a recent diagnosis, off treatment families feel 46% more connected to a community and have 30% more people in their life who can understand what they are going through. Compared to on treatment families, off treatment families also feel 76% more connected to other caregivers of children with cancer. However, restrictions on hospital access and other social isolation measures may have reduced on treatment families' abilities to meet and connect with other caregivers during this time.

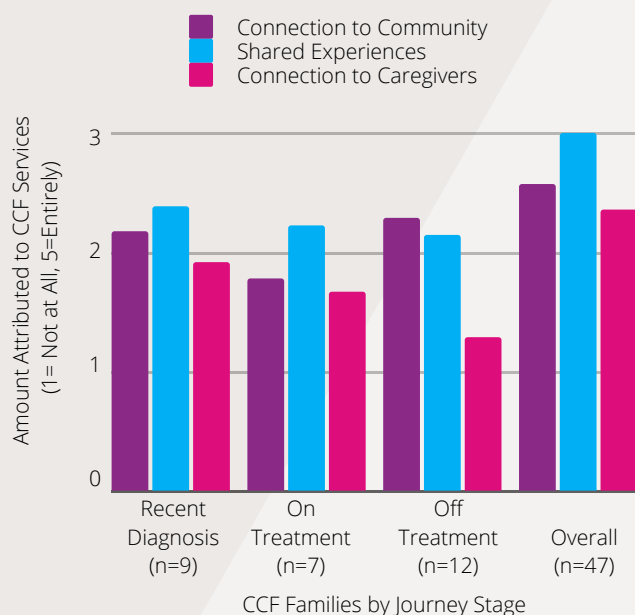
Most off treatment families also attribute their sense connection largely to CCF support. 86% of off treatment families believe CCF helps them to connect with those who can empathise with their experience and 79% of families believe CCF helps them to connect with other caregivers.


*As identified in Red Kite's "The hidden health crisis" report. However, community connections is not correlated with overall wellbeing in this year's measurement.

Types of Community Connections



Attribution of Connections to CCF



A photograph of a family of four sitting outdoors on a wooden deck. A woman with curly hair is holding a baby in a yellow outfit. A young girl is laughing in the center. Another woman with short curly hair is smiling on the right. The photo is partially obscured by a large, semi-transparent white and blue diagonal overlay.

"I don't think we would have survived as a family without the help. Keeping us above water and providing a consistent and friendly ear has meant the world."

- CCF Wellbeing Survey Respondent



Get in Touch



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www.childcancer.org.nz



Huber Social

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Appendices:

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



Huber Social Wellbeing Measurement Framework

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

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

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

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

The Huber Social Wellbeing Measurement Framework

IMPACT

Wellbeing

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

OUTCOMES

Through building Capability

- Resilience
- Life skills
- Wellness - mental, physical and spiritual

OUTCOMES

and providing Opportunity

- Resources
- Self development
- Societal structures
- Relationships



Data Transparency Page

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



Phase	Questions on the Treatment of the Data	Points allocated	Yes or No	
Design	SAMPLE	Everyone in the intervention included in the measurement	2	N
		OR Survey sample population designed to be representative of group	1	Y
		Sample description: <i>Surveys were distributed to 326 families out of the 3794 active between October 2021 and May 2022. 50 surveys were completed for a 15% response rate.</i>	N/A	N/A
	BASELINE	Control group (independent of the intervention)	3	N
		Group baseline measured (pre -intervention)	2	N
		Baseline inferred from time in intervention (e.g. 1 vs. 3 years)	1	Y
EXCLUSIONS	Details of people specifically excluded from the measurement: <i>Surveys were distributed only to families based on selection criteria (had received a diagnosis within the past 3 months, 1-year post-diagnosis, 2-years post diagnosis).</i>	N/A	N/A	
Data Collection	DISTRIBUTION	Online surveys		Y
		OR hardcopy surveys		N
		Data collection supervised by Huber Social consultant	1	N
		Translation or guidance provided	N/A	N/A
	DATA SOURCES	Data mining of other sources	1	Y
		Data included from previous years/measurements	1	Y
	Details of additional data sources: <i>Sample demographics compared to CCF records to assess for generalizability of results. Completion rates compared to that of pilot year's collection.</i>			
Cleaning	CLEANING	Partial responses removed or no partial responses	1	Y
		Details of any responses removed: <i>Partial responses removed if missing >50% Satisfaction with Life Scale data and/or >50% of outcomes data.</i>	N/A	N/A
Analysis	SHIFT MEASUREMENT	Calculated on time in intervention		Y
		Calculated on group average	1	Y
		Calculated based on individual scores	2	N
	TEST APPLIED	Basic analysis		Y
		Statistical Correlation Test	2	Y
	Multiple Regression or Lasso Regression Test	3	N	
Reporting	REPORTING	Client published Outcomes Report (prove)	1	N
		Client received Social Performance Report (improve)	2	Y
		Client published full Social Impact Report	3	Y
RIGOUR SCORE: LOW: 1-9; MED 10-14; HIGH 15-19		MED	13	



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 program 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 program; 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 program 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)

<i>Factor</i>	<i>Stage</i>	<i>Average Score (out of 7)</i>	<i>Attribution Score (out of 5)</i>	<i>Correlation Coefficient</i>	<i>p-value</i>
Hope	All	5.10	2.15	0.518	p<0.01
	Off Treatment	4.43	2.00	0.709	p<0.01
Recover from setbacks	All	4.73	2.23	0.322	p<0.01
	On Treatment	4.57	1.57	0.899	p<0.01
Access to support services*	Recent Diagnosis	5.11	2.67	0.648	p<0.01
Accept child's diagnosis	On Treatment	5.00	2.86	0.809	p<0.01
Feeling overwhelmed by diagnostic information	All	4.47	3.09	-0.266	p<0.01
Anger	All	3.47	2.23	-0.404	p<0.01
	Off Treatment	3.43	2.36	-0.519	p<0.01



Analysis Approach and Results

Table 2. All Attribution Factors

<i>Factor</i>	<i>Stage</i>	<i>Average Score (out of 7)</i>	<i>Attribution Score (out of 5)</i>	<i>Correlation Coefficient</i>	<i>p-value</i>
Access to supportive relationships	All	5.92	3.30	0.391	p<0.01
Access to caregivers of children with cancer diagnosis	All	3.82	1.91	0.286	p<0.01
	All	5.15	3.04	0.420	p<0.01
Access to support services*	Recent Diagnosis	4.89	2.67	0.600	p<0.01
	Off Treatment	5.14	3.21	0.681	p<0.01
Opportunity to maintain physical wellness	All	4.91	2.08	0.365	p<0.01
	On Treatment	5.43	2.00	0.741	p<0.01
Able to spend quality time with their partner	On Treatment	4.14	2.14	0.702	p<0.01
Ability to manage emotions	On Treatment	6.00	1.71	0.671	p<0.01
Ability to manage financial situation	Off Treatment	4.67	2.79	-0.593	p<0.01



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 2022 and (2) Family Wellbeing Check (Bereavement) 2022. 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).
- Program 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 program 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 CCF Wellbeing Survey.

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

Survey Testing and Validation

To ensure the survey questions are culturally, linguistically and ethically appropriate, and that all survey questions are understood by participants, surveys are tested and validated with select individuals from the measurement group before rolling out to the entire sample. Survey piloting was completed in the pilot measurement, but was not repeated for this year's measurement. However, survey review and refinement was conducted at the start of this year's measurement from August - September 2021.



Child Cancer Foundation - Family Wellbeing Check 2022

Introduction Page

1. **YOUR CONSENT**

Before we start, we need to confirm that you agree to participate in this survey. Please read the following and click 'Yes' if you are happy to continue with the survey.

I understand and agree that:

- I have read the above information about the survey
- The survey is entirely voluntary and I may choose to stop at any time
- Results may be made public, however my responses are confidential and individuals will never be identified in any reporting
- My de-identified survey response will be collected and securely lodged with the Huber Social Database (please contact Huber Social if you would like more information)

Please click '**YES**' to indicate your consent and start the survey. *

- Yes
- No - end the survey

Information About You and Your Child

2. To protect your privacy and to ensure you feel comfortable providing honest answers, this survey will remain anonymous to both Huber Social and Child Cancer Foundation. However, we do need a way to track your progress throughout your child's journey with cancer.

You have been provided a unique ID number in the survey email.

Please enter the unique ID number here. *

3. Where do you currently live?

(Please select closest location if exact location is not in the list)

- Auckland
- Central Otago
- Christchurch
- Dunedin
- Eastern Bay of Plenty
- Hawkes Bay
- Lakes
- Manawatu
- Marlborough
- Nelson
- Northland
- South Canterbury
- Southland
- Tairāwhiti
- Taranaki
- Tauranga
- Waikato
- Wairarapa
- Wellington
- West Coast
- Whanganui

4. What ethnicity group do you identify with?

- New Zealand Māori
- New Zealand European/Pākehā
- Samoan
- Cook Island Māori
- Tongan
- Niuean
- Chinese
- Indian
- Another ethnicity (e.g. Dutch, Japanese, Tokelauann)

5. Right now I am feeling...

(Select the image you feel closest to)



6. How old is your child?

7. What gender does your child identify with?

- Female
- Male
- Another - Write In

8. What is your relationship to your child who has or has had a confirmed cancer diagnosis?

- Parent
- Grandparent
- Other - Write In

9. Monitoring Wellbeing and Needs Across your Cancer Journey

We understand that the needs of a child and their caregiver change as they move through their cancer journey. While this is an individual journey and looks different for everyone, we have created some key points in the journey that apply to the majority of families.

We are asking you to complete the Child Cancer Foundation Wellbeing Survey at these points so that we can determine what matters most to the wellbeing of caregivers at different points in your journey, and to ensure Child Cancer Foundation is using its resources in the best possible way to meet your needs.

Please select the point below that most closely aligns to where you and your child are in their cancer journey: *

- On-treatment (is currently receiving treatment for a cancer diagnosis)
- Off-treatment (has completed treatment of a cancer diagnosis)

10. What was the date your child was first diagnosed?

(Please estimate if exact date unknown)

11. Has your child's cancer relapsed and are they back on treatment?

- Yes
- No

12. Please assess your level of agreement with the following statement:

My child's cancer treatment is progressing as planned.

- Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree

13. What was the date your child completed treatment?

(Please estimate if exact date unknown)



14. In the past week, have you been living away from your usual whānau and/or support network in order to receive treatment?

- Yes
 No

15. In the past six months, have you had a connection with or support from Child Cancer Foundation in any of the following ways:

Please select all that apply.

- Family Support Coordinator
- Connection with other families via a Whānau Connect Group
- Beads of Courage Program
- Webinar series
- Another type of connection (please specify)
- No involvement with Child Cancer Foundation in the past six months

16. You have indicated that you have not had any involvement with Child Cancer Foundation in the past six months.

When was the last time you engaged with Child Cancer Foundation? Please select the closest option:

- 1 year ago
- 2 years ago
- 3 years ago or more

17. Has your child experienced any late effects due to their cancer treatment?

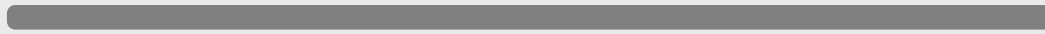
- Yes
- No

18. What late effects has your child experienced?

Relationships and Connection

19. I have people in my life who help and support me.

Strongly disagree



Strongly agree

Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all
- A little bit
- Somewhat
- A lot
- Completely

20. I get to spend quality time with people in my support network.

Strongly disagree



Strongly agree

Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

21. I get to spend quality time with my child/children.

Strongly disagree



Strongly agree

Neither agree nor disagree

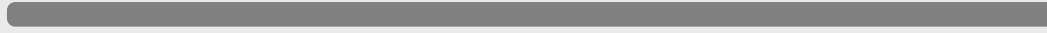
How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

22. I get to spend quality time with my partner.

Please skip this question if you do not have a significant other.

Strongly disagree



Strongly agree

Neither agree nor disagree

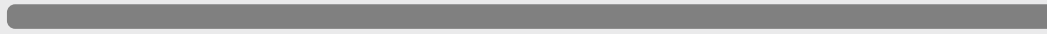
How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

23. My relationship with my partner is struggling due to the pressures we are under from my child's cancer diagnosis.

Please skip this question if you do not have a significant other.

Strongly disagree



Strongly agree

Neither agree nor disagree

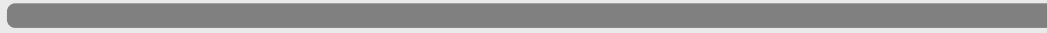
How much has Child Cancer Foundation helped you to manage this?

- Not at all A little bit Somewhat A lot Completely

24. I feel connected to a community.

(A community is a group who you share interests or attitudes with, for example friends, cultural groups, religious groups, sport clubs or neighbourhood groups).

Strongly disagree



Strongly agree

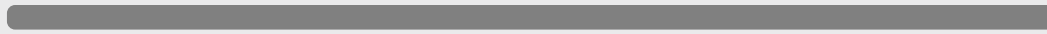
Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

25. There are people in my life who understand how I feel.

Strongly disagree



Strongly agree

Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

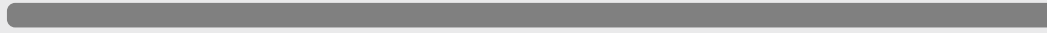
- Not at all A little bit Somewhat A lot Completely

26. Please specify all of the people or relationships in your life who understand how you feel:

- My partner
- My family or whānau
- Friendships created through local Whānau Connect Group
- Friendships created since child's cancer diagnosis
- Another (please specify)

27. Lately, I have had the opportunity to talk to other caregivers of children with a confirmed cancer diagnosis.

Strongly disagree



Strongly agree

Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all
- A little bit
- Somewhat
- A lot
- Completely

28. Please select all of the places where you've been able to connect with other caregivers through Child Cancer Foundation:

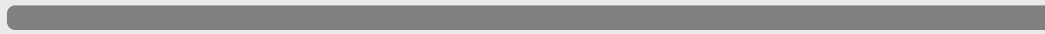
- At a Connect Group event
- At the Ronald McDonald House or a Family Place
- At the hospital where my child is receiving treatment
- Via Facebook or other CCF social media groups
- Another place or event (please specify)

Support Services and Resources

29. I am able to access the support services I need.

(Support services include but are not limited to health care, financial, education, employment, healthy homes and spiritual services).

Strongly disagree



Strongly agree

Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all
- A little bit
- Somewhat
- A lot
- Completely

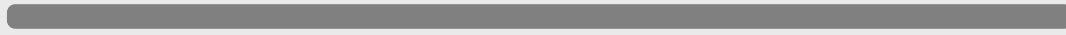
30. Please select all of the Child Cancer Foundation services that you have utilised:

- Family Support Coordinators
- Whānau Connect Groups
- Family Places
- Counselling
- Dad's Support Network
- Health management information (via webinars and other resources)
- Short-term financial support
- Use of temporary housing
- Use of Holiday Homes
- Wellbeing Information
- Personal Development
- Grants
- Access to Respite
- Another service (please specify)

31. What additional support services do you require more access to? Please specify:

32. I am treated with respect by the Family Support Coordinator working with my child.

Strongly disagree

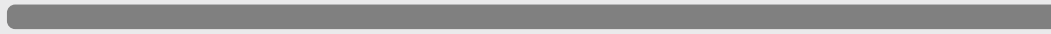


Neither agree nor disagree

Strongly agree

33. I feel overwhelmed by the amount of information I am given about managing my child's cancer diagnosis

Strongly disagree



Neither agree nor disagree

Strongly agree

How much has Child Cancer Foundation helped you to manage this?

- Not at all A little bit Somewhat A lot Completely

34. What has been the most helpful information Child Cancer Foundation provided to help you manage your child's cancer diagnosis?

35. Were you offered access to counselling services at any point in your child's cancer journey?

- Yes
- No
- I'm not sure

36. How well did those counselling services meet your needs?

- Not at all
- A little bit
- Somewhat
- A lot
- Completely

37. Do you know how to access counselling services through Child Cancer Foundation?

- Yes
- No
- I'm not sure

38. What is the quality of resources you have access to through Child Cancer Foundation when living away from home while your child received treatment?

Please comment on which ones you found most helpful.

	No access at all	Poor quality	Average quality	High quality
Hospital meals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Toiletries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Entertainment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments

39. When living away from home so your child can receive treatment, do you have access to the right technology to stay in touch with your family and friends?

- Yes
- No

40. What other technology resources do you need access to while living away from home for your child's treatment?

41. Have you had the opportunity to attend a Child Cancer Foundation Wellbeing Workshop?

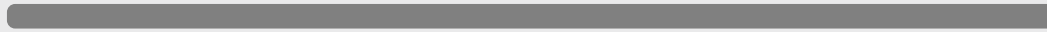
- Yes
- No

42. Please share how these events were helpful to you in your family's cancer journey.

Resilience and Being a Caregiver

43. I have the skills to care for a child who has or has had a cancer diagnosis.

Strongly disagree



Neither agree nor disagree

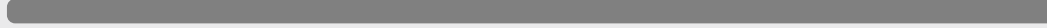
Strongly agree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

44. I can understand and manage my financial situation.

Strongly disagree



Strongly agree

Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

45. I have the opportunity to maintain my physical wellness.

Strongly disagree



Strongly agree

Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

46. Recently, I have had moments of joy.

Strongly disagree



Strongly agree

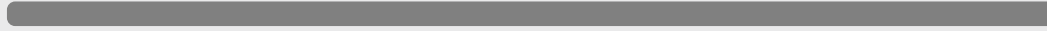
Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

47. Recently, I have been feeling anxious.

Strongly disagree



Strongly agree

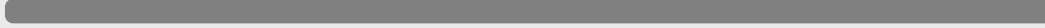
Neither agree nor disagree

How much has Child Cancer Foundation helped you to manage this?

- Not at all A little bit Somewhat A lot Completely

48. Recently, I have been feeling angry.

Strongly disagree



Strongly agree

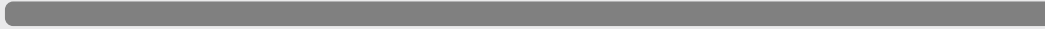
Neither agree nor disagree

How much has Child Cancer Foundation helped you to manage this?

- Not at all A little bit Somewhat A lot Completely

49. I have things to hope for.

Strongly disagree



Strongly agree

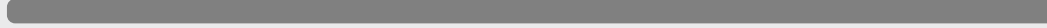
Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

50. I have the time and energy to look after myself.

Strongly disagree



Strongly agree

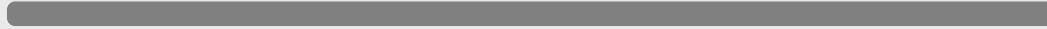
Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

51. At times I feel helpless.

Strongly disagree



Strongly agree

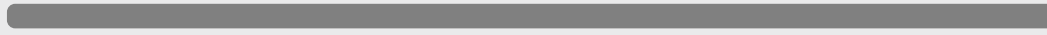
Neither agree nor disagree

How much has Child Cancer Foundation helped you manage this?

- Not at all A little bit Somewhat A lot Completely

52. I have learnt ways to help me manage my emotions.

Strongly disagree



Strongly agree

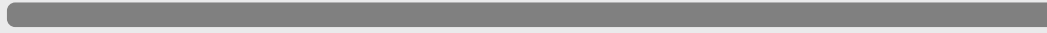
Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

53. I have been able to emotionally accept my child's cancer diagnosis.

Strongly disagree



Strongly agree

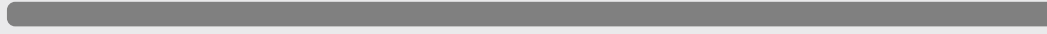
Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

54. I feel I can handle many things at a time.

Strongly disagree



Strongly agree

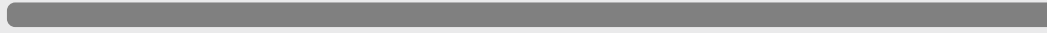
Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

55. I tend to recover quickly after setbacks.

Strongly disagree



Strongly agree

Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

56. I can adapt when unexpected events happen.

Strongly disagree



Strongly agree

Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

57. What else has helped you remain resilient through your family's journey with cancer?

Satisfaction with Life

58. In most ways my life is *not* close to my ideal.

Strongly disagree



Strongly agree

59. The conditions of my life are quite poor.

Strongly disagree

Strongly agree

60. I am not satisfied with my life.

Strongly disagree

Strongly agree

61. So far I have not achieved the important things I want in life.

Strongly disagree

Strongly agree

62. If I could live my life over, I would change almost everything.

Strongly disagree

Strongly agree

Feedback and final questions

63. In your own words, how has Child Cancer Foundation had an impact on your life?

64. Overall, would you rate your experience with Child Cancer Foundation as:

- Positive
- Neutral
- Negative

65. Do you have any feedback, suggestions or comments for Child Cancer Foundation?
(Please note, as surveys are anonymous we will not be able to reply to any specific questions.)

Child Cancer Foundation - Family Wellbeing Check (Bereavement) 2022

Introduction Page

1. **YOUR CONSENT**

Before we start, we need to confirm that you agree to participate in this survey. Please read the following and click 'Yes' if you are happy to continue with the survey.

I understand and agree that:

- I have read the above information about the survey
- The survey is entirely voluntary and I may choose to stop at any time
- Results may be made public, however my responses are confidential and individuals will never be identified in any reporting
- My de-identified survey response will be collected and securely lodged with the Huber Social Database (please contact Huber Social if you would like more information)

Please click '**YES**' to indicate your consent and start the survey. *

- Yes
- No

Details

2. To protect your privacy and to ensure you feel comfortable providing honest answers, this survey will remain anonymous to both Huber Social and Child Cancer Foundation. However, we do need a way to track your progress throughout your child's journey with cancer.

You have been provided a unique ID number in the survey email.

Please enter the unique ID number here. *

3. Right now I am feeling...

(Select the image you feel closest to)



4. What was the date of your child's death?

*



5. How old was your child when they passed away?

6. In the past six months, have you had a connection with or support from Child Cancer Foundation in any of the following ways:

Please select all that apply. *

- Family Support Coordinator
- Connection with other families via a Whānau Connect Group
- Webinar series
- Another type of connection or support (please specify)
- No involvement with Child Cancer Foundation in the past six months

7. You indicated you have had no involvement with Child Cancer Foundation in the last six months.

Have you had any involvement with Child Cancer Foundation since your child passed away?

- Yes
- No

8. If yes, at what point and why did your involvement with Child Cancer Foundation stop?

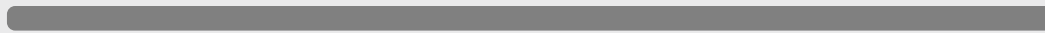
9. Are you currently seeing a counselor or psychologist?

- Yes
- No

Relationships and Connection

10. I spend quality time with people I care about.

Strongly disagree



Strongly agree

Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all
- A little bit
- Somewhat
- A lot
- Completely

11. I have people in my life who help and support me.

Strongly disagree



Strongly agree

Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

12. I have someone who will listen when I need to talk about my worries and problems.

Strongly disagree



Strongly agree

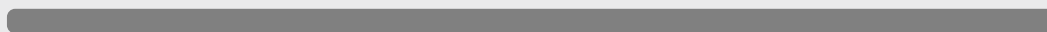
Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

13. There are people in my life who understand how I feel.

Strongly disagree



Neither agree nor disagree

Strongly agree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

14. Please select all of the people and/or relationships that supported you during this difficult time:

- My partner
- My family or whānau
- Friendships created through my local Connect Group
- Friendships created since child's cancer diagnosis
- Another person or relationship (please specify)

15. My family look out for each other.

Strongly disagree



Strongly agree

Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

16. I find it difficult to relate to other members of my family.

Strongly disagree



Strongly agree

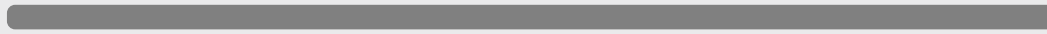
Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

19. Lately, I have had the opportunity to talk to other caregivers who have lost a child to cancer.

Strongly disagree



Strongly agree

Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

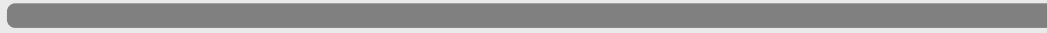
20. Please select all of the places where you've been able to connect with other caregivers through Child Cancer Foundation:

- At a Connect Group event
- Via Facebook or other CCF social media groups
- Another way (please specify)

21. I feel connected to a community.

(A community is a group who you share interests or attitudes with, for example friends, cultural groups, religious groups, sport clubs or neighbourhood groups).

Strongly disagree



Strongly agree

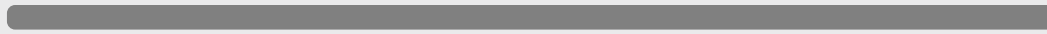
Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

22. I feel lonely

Strongly disagree



Strongly agree

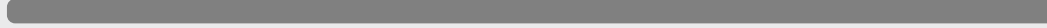
Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

23. I still have contact with the healthcare team that cared for my child.

Strongly disagree



Strongly agree

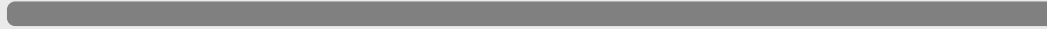
Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

24. I know of grief and bereavement support services I can use if I want to.

Strongly disagree



Strongly agree

Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

25. Have you used bereavement support services offered by Child Cancer Foundation?

- Yes
- No

26. How well did those bereavement support services meet your needs?

- Not at all
- A little bit
- Somewhat
- Very much
- Completely

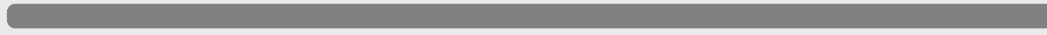
27. Have you attended a Child Cancer Foundation Bereaved Parents Weekend?

- Yes
- No

28. Please share how this event has helped you in processing your child's passing.

29. I am able to do what is necessary to run my household, for example cooking, cleaning, paying bills, shopping.

Strongly disagree



Strongly agree

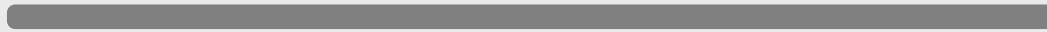
Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

30. Recently, I have had moments of joy.

Strongly disagree



Strongly agree

Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

31. Recently, I have been feeling anxious.

Strongly disagree



Strongly agree

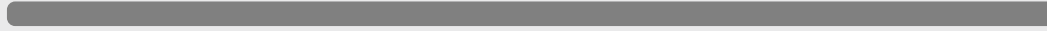
Neither agree nor disagree

How much has Child Cancer Foundation helped you to manage this?

- Not at all A little bit Somewhat A lot Completely

32. Recently, I have been feeling angry.

Strongly disagree



Strongly agree

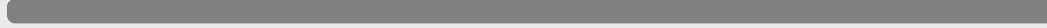
Neither agree nor disagree

How much has Child Cancer Foundation helped you to manage this?

- Not at all A little bit Somewhat A lot Completely

33. I have difficulty accepting my child's death.

Strongly disagree



Strongly agree

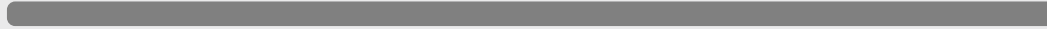
Neither agree nor disagree

How much has Child Cancer Foundation helped you to manage this?

- Not at all A little bit Somewhat A lot Completely

34. I have learnt ways to help me manage my emotions.

Strongly disagree



Strongly agree

Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

35. I have things to hope for.

Strongly disagree



Strongly agree

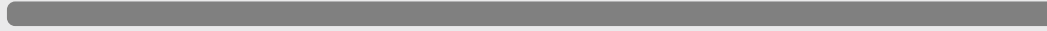
Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

36. I have the time and energy to take care of myself.

Strongly disagree



Strongly agree

Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

37. I have the opportunity to maintain my physical wellness.

Strongly disagree



Strongly agree

Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

38. I feel I can handle many things at a time.

Strongly disagree



Strongly agree

Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

39. I tend to recover quickly after setbacks.

Strongly disagree



Strongly agree

Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

40. I can adapt when unexpected events happen.

Strongly disagree



Strongly agree

Neither agree nor disagree

How much has Child Cancer Foundation helped you with this?

- Not at all A little bit Somewhat A lot Completely

41. What else has helped you remain resilient in processing your child's passing?

Palliative Care

Enter another option

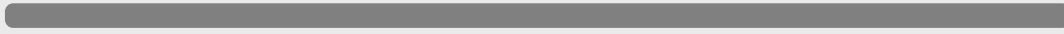
Enter another option



Satisfaction with Life Questions

43. In most ways my life is *not* close to my ideal.

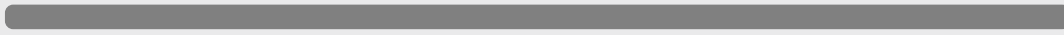
Strongly disagree



Strongly agree

44. The conditions of my life are quite poor.

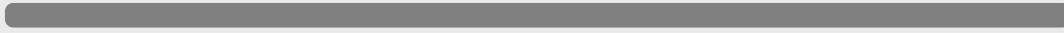
Strongly disagree



Strongly agree

45. I am not satisfied with my life.

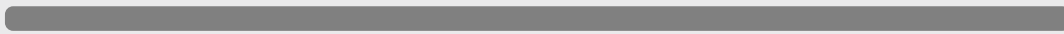
Strongly disagree



Strongly agree

46. So far I have not achieved the important things I want in life.

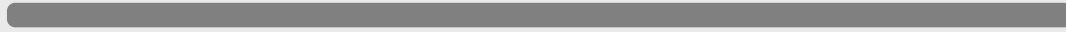
Strongly disagree



Strongly agree

47. If I could live my life over, I would change almost everything.

Strongly disagree



Strongly agree

Feedback and Final Questions

48. In your own words, how has Child Cancer Foundation had an impact on your life?

49. Overall, how would you rate your experience with Child Cancer Foundation?

- Positive
- Neutral
- Negative

50. Do you have any feedback, suggestions or comments for Child Cancer Foundation?
(Please note, as surveys are anonymous we will not be able to reply to any specific questions)

51. What is your relationship to your child who passed from a cancer diagnosis?

- Parent
- Grandparent
- Other - Write In

52. Where do you currently live?

(Please select closest location if exact location is not in the list)

- Auckland
- Central Otago
- Christchurch
- Dunedin
- Eastern Bay of Plenty
- Hawkes Bay
- Lakes
- Manawatu
- Marlborough
- Nelson
- Northland
- South Canterbury
- Southland
- Tairāwhiti
- Taranaki
- Tauranga
- Waikato
- Wairarapa
- Wellington
- West Coast
- Whanganui

53. What ethnicity group do you identify with?

- New Zealand Māori
- New Zealand European/Pākehā
- Samoan
- Cook Island Māori
- Tongan
- Niuean
- Chinese
- Indian
- Another ethnicity (e.g. Dutch, Japanese, Tokelauann)