HUBER SOCIAL

Child Cancer Foundation Social Impact

Child cancer FOUNDATION

Service Performance Results

June 2022

Contents

About This Report

Key highlights

- This is the second year of CCF measuring its social impact with Huber Social.
- The report results evidence the impact of CCF's work and identify opportunities for focusing future efforts to further maximise their impact
- Results may also reflect the impact that COVID-19 had on access to CCF services during the reporting year

- To strengthen the empirical evidence of its impact, Child Cancer Foundation (CCF) partnered with social impact measurements Huber Social in 2020 to establish a measurement system that aims to demonstrate (measure) the social impact of CCF and identify opportunities to maximise that impact.
- Results of this measurement system can support CCF to inform internal decision making, strengthen support from donors, identify opportunities to collaborate with others as well as satisfy requirements of the new accounting standards.
- 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. Many CCF services were impacted by the restrictions placed on domestic travel, hospital access and social distancing measures. This limited access may likely be reflected in the results with respect to CCF service utilization.

CCF Vision:

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

How We Measured the Social Impact of Child Cancer Foundation

- The Huber Social Wellbeing Measurement Framework
- CCF Social Impact Thesis
- About the Measurement
- About the Survey Respondents

The Huber Social Wellbeing Measurement Framework

Recognising the goal for each of us is the same, Huber Social measures:

- Progress overall in terms of a ‘shift’ in overall wellbeing; and
- What people need, in terms of capability and opportunity, to maximise wellbeing.

Using a standardised process, data is collected from the people directly impacted.

Statistical analysis is used to identify which outcomes are correlated with wellbeing.

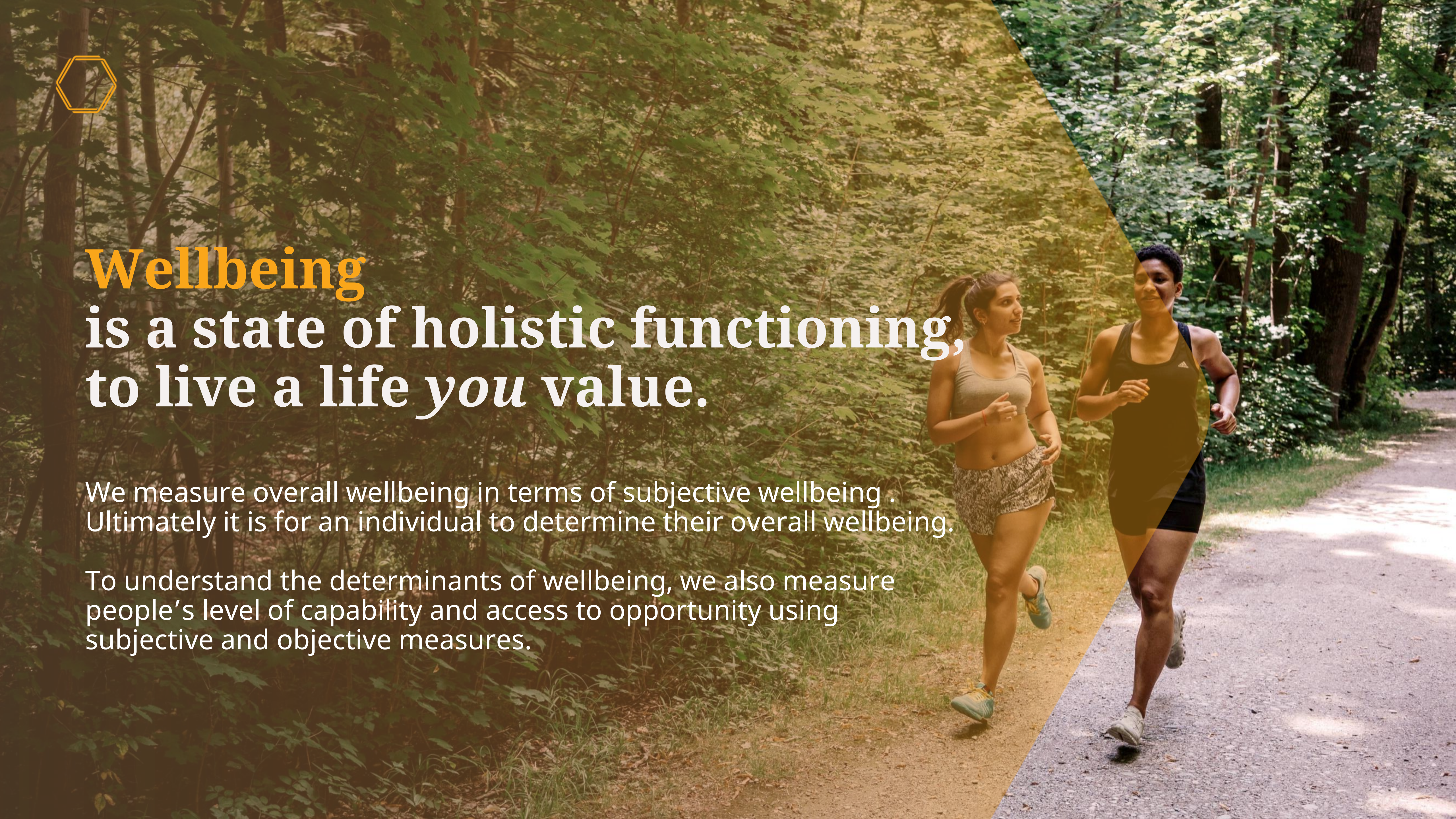
This tells us what matters most to their overall wellbeing, and where resources should be directed to have the maximum impact.

The Huber Social Wellbeing Measurement Framework™

Impact
Wellbeing

Outcomes
Through building
Capability
Wellness
Life skills
Resilience

Outcomes
and providing
Opportunity
Resources
Structures & Services
Self-development
Relationships



Wellbeing is a state of holistic functioning, to live a life *you* value.

We measure overall wellbeing in terms of subjective wellbeing . Ultimately it is for an individual to determine their overall wellbeing.

To understand the determinants of wellbeing, we also measure people’s level of capability and access to opportunity using subjective and objective measures.

CCF Social Impact Thesis

Child Cancer Foundation’s social impact thesis was developed through co-design workshops with CCF staff.

For the full impact thesis, including outputs, activities and resources, please see the CCF Measurement Plan.

	THEORY OF CHANGE	METRICS	
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.	• % shift in Huber Social subjective wellbeing measures	
2. Outcomes	The program achieves this through the following outcomes: • Healthy relationships • Community connection and belonging • Access to societal structures • Life skills and knowledge • Resilience • Positive mental, emotional and physical wellness • Access to resources • Access to self-development and self-expression opportunities	Increase in capabilities: **Community connection** • Community connection • Access to community **Resilience** • Self-belief • Coping • Adaptability **Life skills** • Health management • Financial literacy • Parenting **Holistic wellness** • Emotional wellness • Hope • Vulnerability • Physical health	Increase in opportunities: **Relationships** • Family connection • Communication skills • Access to personal relationships **Social structures** • Support systems • Healthcare services • Safe and healthy home • Flexible employment **Resources** • Nutrition • Shelter • Communication tools • Income **Self-development** • Emotional • Social • Self-respect

About the Measurement

Response rate

- In total, 50 surveys were completed by families of the 326 for a response rate of 15%
  - 47 out of 310 surveys were completed by families for a response rate of 14%
  - 3 out of 16 surveys were completed by bereaved families for a response rate of 19%
- This marks an improvement from the pilot year's response rate (9%)
- While low, this response rate is comparable to those of other studies with this population (Red Kite achieved 20% response rate)

Survey distribution

- Surveys were distributed by CCF via email from October 2021 to May 2021.
- Surveys were sent to families as they reached various timings in their cancer journey:
  - Recent diagnosis (within the past three months)
  - 1 year post diagnosis
  - 2 years post diagnosis

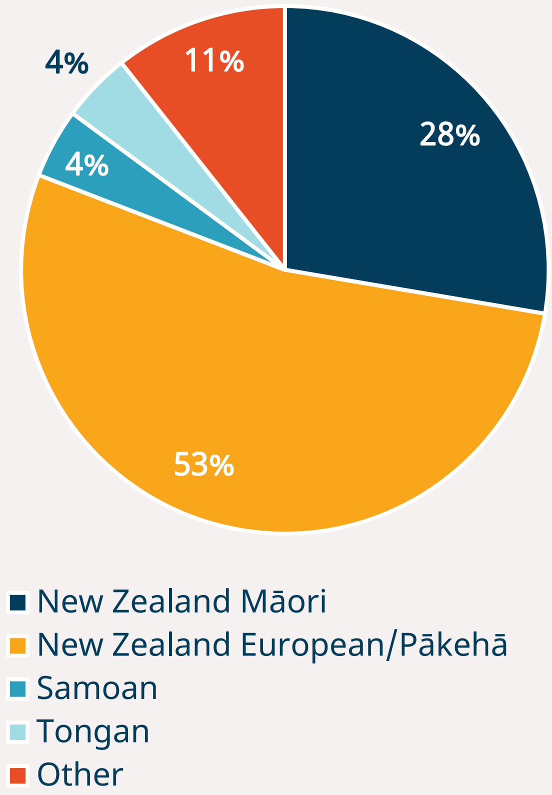
Measurement groups (for assessing impact)

- 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): Having received a cancer diagnosis within the past 3-6 months (n=9)
  - On treatment: Having been on treatment for a cancer diagnosis approx. 1 year (n=7)
  - Off treatment: Having completed cancer treatment within the past year (n=14)
  - Bereavement: Having lost a child within the past 18 months (n=3)

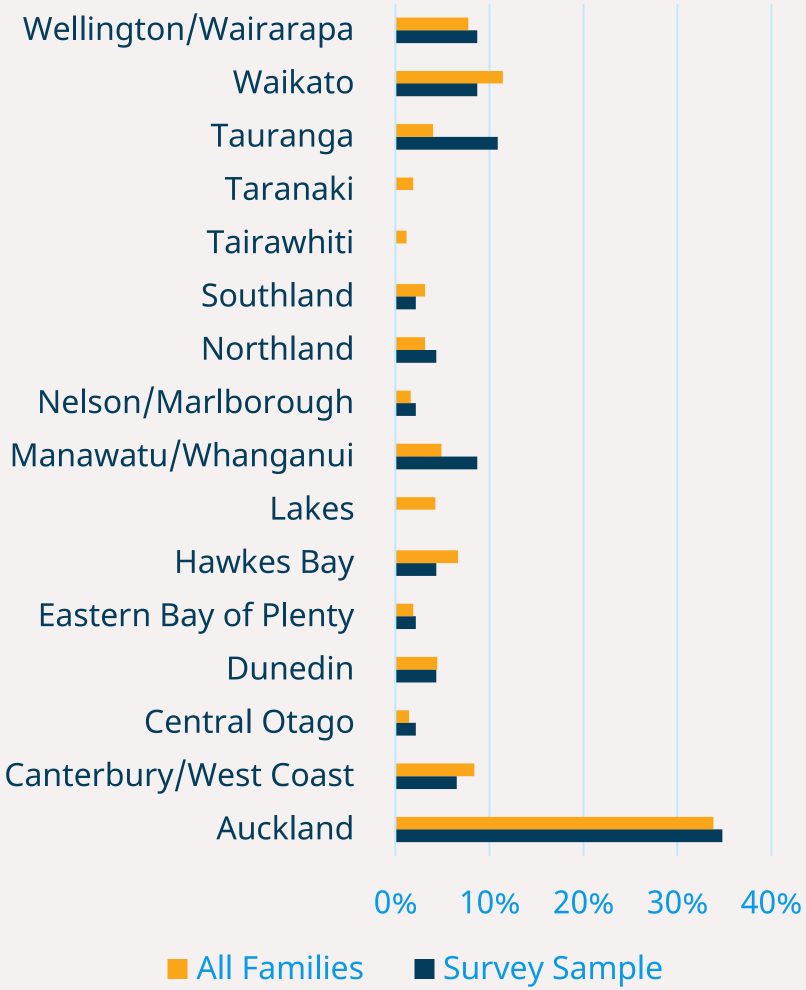
About the Survey Respondents

- Majority (58%) of respondents have children still undergoing treatment
- Nearly all are/were parents to child with cancer diagnosis (98%)
- ¼ respondents are New Zealand Māori
  - Other ethnicities include Chinese and European
- Sample is largely representative of all CCF families from May 2021- May 2022
  - Largest difference in Tauranga (7% overrepresentation in survey)
  - No representation from Lakes, Tairawhiti or Taranaki in survey

Respondents by Ethnicity



% of Respondents by Location



Service Performance Results

- Overall Impact
- Child Cancer Foundation Goals
- Qualitative Feedback

Key Findings

- The following are key high-level findings that provide evidence supporting Goals 1 and 3
- All findings reported are statistically significant (p<0.1), unless otherwise indicated (*)
- The following sections explore these findings and additional data to support the impact of CCF's work

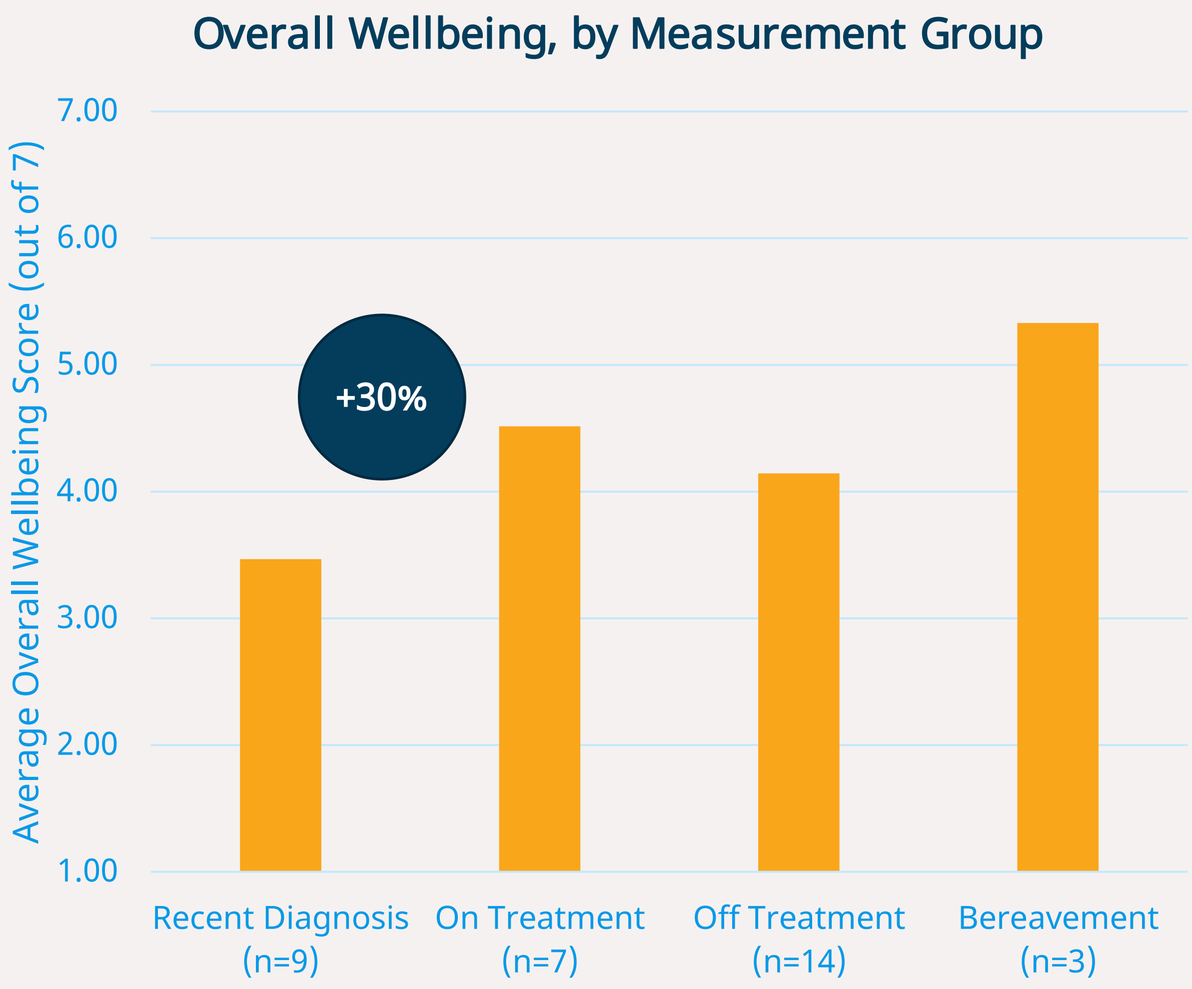
- **Child Cancer Foundation supports new families to access key services**
  - For new families, access to key resources and utilization of more support services is associated with higher wellbeing
  - 89% of new families believe that CCF helps them access the services they need
- **Child Cancer Foundation 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
- **Child Cancer Foundation supports off-treatment families to nurture their personal relationships**
  - Off-treatment families are able to spend more time with their children (24%) and have more supportive relationships (18%) compared to new families
  - 100% of families also believe CCF has helped them to develop and maintain these relationships*
- **Child Cancer Foundation helps all families manage their child's 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*

Overall Impact

- Overall Wellbeing
- Overall Satisfaction with CCF
- Attribution of CCF Services

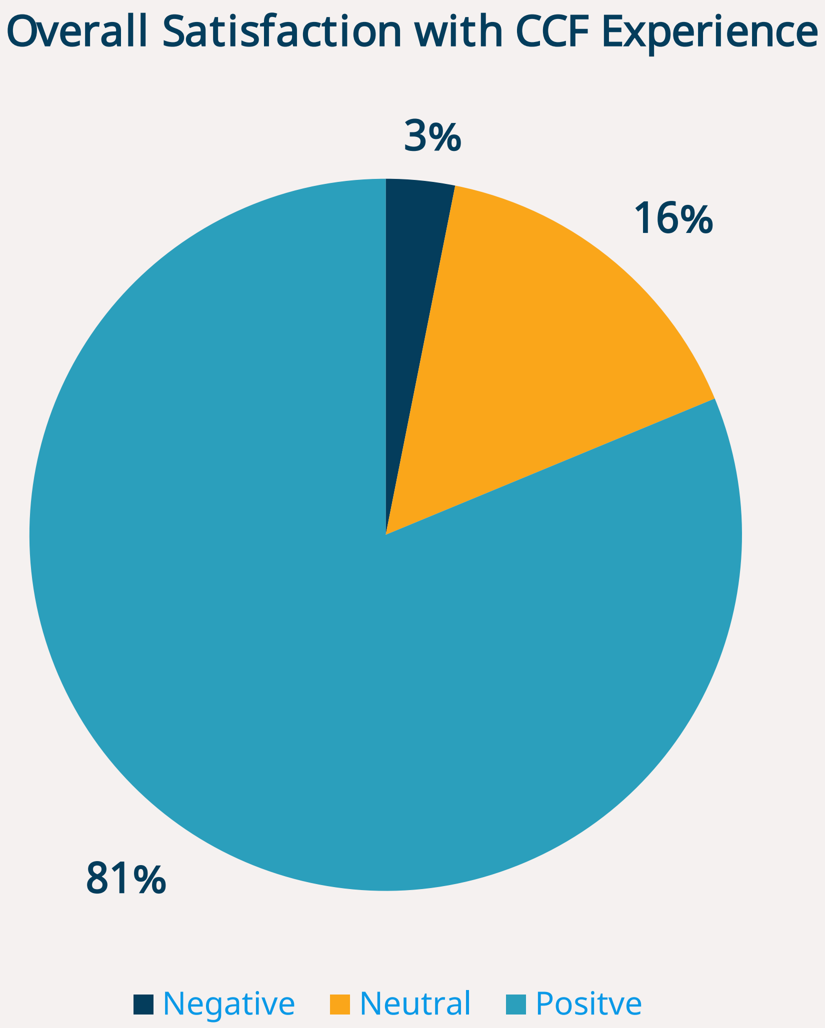
Overall Wellbeing by Measurement Group

- Measured using the SWLS but items were reversed
- Compared to families with a recent cancer diagnosis, families 1-year into treatment had 30% higher wellbeing (p<0.01)
- There was no significant difference in overall wellbeing between on treatment and off treatment groups
- Bereaved families have higher wellbeing, but the sample size is very small (n=3)



Overall Satisfaction with CCF

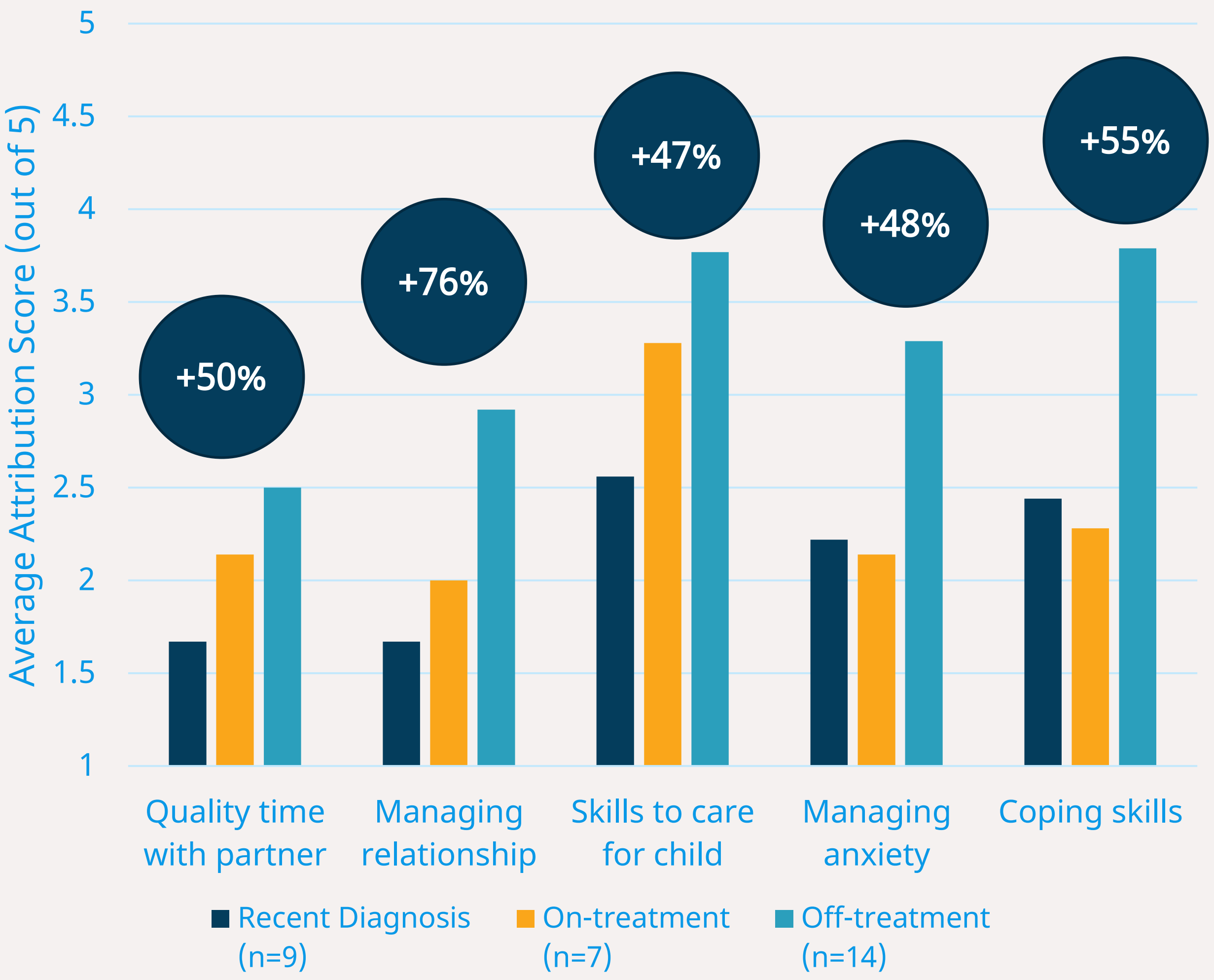
- 4/5 of participants have had a positive experience with Child Cancer Foundation
- Feedback from negative and neutral experience included:
  - Being referred to CCF services too late in journey
  - Not receiving the type of financial support requested
  - Feeling overwhelmed by the amount of contact received from CCF
- No significant difference by measurement group



Where Respondents Feel Most Supported by CCF

- Average attribution of CCF to the wellbeing needs of respondents is about 50% (2.49 out of 5)
  - Factors range from 36% (adaptability) to 66% (supportive people)
- On average off-treatment families attribute 25% more support to CCF compared to new families (p<0.05)
- Quality time with partner and managing relationships are priority needs for new families

Significant Increases in Attribution from Baseline to Off-treatment



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

Supported Families

Proposed CCF metrics

- Number of families supported through contact with an FSC
- Practical support provided
- Psychosocial support provided

Huber Social proposes including the following additional metrics from our social impact measurement research:

- Families have access to the services they need
- Families have strengthened their holistic wellness and resilience
- Families have improved their skills to care for their child and family

1.

Access to key CCF services

Metrics:

- % of CCF services utilised, by type
- Quality of services
- % change across key program outcomes related to CCF services by journey stage
- % CCF support attributed to services highly correlated with wellbeing

2.

Strengthened holistic wellness and resilience

Metrics:

- % change in holistic wellness and resilience outcomes by journey stage
- % CCF support attributed to wellness factors associated with high wellbeing

3.

Improved life skills

Metrics:

- % change in key daily life skills by journey stage
- % CCF support attributed to life skills found to have a high correlation with wellbeing

Access to CCF Services

Key findings:

- Family Support Coordinator (FSC) is the most utilized service
  - 97% of families report being treated with respect by their FSC
- Only 54% of families report being able access to the services they need
  - When asked what additional services are needed, none were specified
  - This may be indicative of limited access to services due to COVID – only FSC's were operating remotely at this time

Support services utilized in the past six months

- 94% of family respondents have connected with an FSC
- 64% with Beads of Courage
- On average, families have used 2 CCF support services

Types of CCF services utilized (ever)

- 81% have connected with their FSC
- 38% have utilized short-term financial support
- 26% have utilized counselling services
- 21% have utilized wellbeing information
- 15% have utilized grants

Counselling services

- When asked if they had been offered counselling services, 60% of respondents said yes
- Of those who had not been offered or were unsure, only 16% knew how to access counselling services
- Of those who had used counselling services, almost 50% said the counselling services met their needs

Quality of resources when living away

- On average, respondents said that toiletries were of high quality; hospital meals and entertainment of average quality
- All families had access to the right technology to stay in touch with family members and friends

CCF Wellbeing Workshops

- Only 4% of respondents have had the chance to attend a workshop

Access to CCF Services and Wellbeing

Key findings:

- For new families, access to key resources and utilization of more support services is associated with higher wellbeing
- The more CCF helps new families to use key support resources, the more likely they are to use those resources and therefore have improved wellbeing
- 89% of new families believe that CCF helps them access the services they need

New families (recent diagnosis)

- Analysis results found that for families who have recently received a cancer diagnosis, **the more CCF services they use the higher their wellbeing** is likely to be (b=0.734, $p<0.05$).
  - Access to key support services is also found to be positively correlated with wellbeing (b=0.648, $p<0.1$)
  - Results show that CCF support is also correlated with accessing these resources (b=0.600, $p<0.1$)
- This means that the more CCF supports new families to use the resources, the more likely they are to use these resources and therefore the more likely they are to have higher wellbeing
- On average new families feel somewhat confident in their ability to access services (5.11 out of 7)
  - 89% of new families believe that CCF supports them at least a little bit in accessing the support services they need
- There was no significant association found between service utilisation and wellbeing of on-treatment or off-treatment families

Holistic Wellness and Resilience

Key findings

- Overall, holistic wellness and resilience was found to be significantly correlated with overall wellbeing (p<0.1)
- One year after a cancer diagnosis, families feel over 50% more hopeful
- Over 2/3 of all families believe that CCF supports them to manage their hope and anger throughout their journey

Holistic Wellness

- **Hope** was found to be correlated with high wellbeing for families overall, particularly for off-treatment families and bereaved families
  - While on treatment families have 51% higher sense of hope than new families, this decreases by 23% among off-treatment families (p<0.01)
  - However, bereaved families have the highest sense of hope (5 out of 7)
- **Anger** was found to be negatively correlated with high wellbeing for all families
  - The more frequently a family feels angry, the lower their wellbeing is likely to be, particularly for off-treatment families and bereaved families
  - Both on and off-treatment families feel 10% less angry than new families (p=0.11)
- Over 2/3 (68%) of all families believe that CCF supports them with maintaining hope and managing their anger at least a little bit
  - However, CCF support was not significantly correlated with families' sense of hope or anger at any stage (p>0.1)

Resilience

- **Recovery from setbacks** was found to be correlated with high wellbeing for families overall, particularly for those on treatment (p<0.01)
  - On-treatment families are mildly confident in their ability to recover from setbacks (4.57 out of 7)
  - 1/3 of families on treatment believe that CCF supports them with this type of resilience, but is not significantly correlated (p>0.1)

How Families Remain Resilient

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

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

Daily Life
Skills

Key findings

- For families at any stage, feeling overwhelmed by diagnosis information is associated with lower wellbeing
  - 95% of families believe that CCF helps them feel less overwhelmed
- For new families, feeling confident in their ability to manage their financial situation is important to wellbeing and 2/3 of them feel that CCF supports them to do so

Managing diagnostic information

- 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 ($b=-0.266$, $p<0.1$)
- 95% of all family respondents believe that CCF supports them at least a little bit in understanding and processing information received about their child's medical diagnosis.
  - However, CCF support was not found to be significantly correlated with managing medical information ($p>0.1$)

Managing financial situations

- For new families, feeling supported by CCF in understanding how to manage their financial situation was positively correlated with wellbeing ($b=0.595$, $p<0.1$)
- 2/3 of new families feel that CCF supports them to manage their finances
- However, new families are 22% less confident in their ability to manage their financial situation compared to families that have completed treatment ($p<0.1$)

Accepting a Diagnosis and Wellbeing

Key Findings

- Emotional acceptance of a child’s diagnosis is considered a life skill capability within the CCF impact thesis
- The more CCF supports on-treatment families to accept their child’s diagnosis, the more likely these families will be able to do so and the higher their wellbeing is likely to be
- However, acceptance of a child’s diagnosis is a continued struggle for many on treatment families

Accepting a diagnosis

- For on-treatment families, being able to emotionally accept their child’s diagnosis was associated with higher wellbeing (b=0.809, p<0.05)
  - 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 are only slightly able to accept their child’s diagnosis (5 out of 7)
- There is no significant difference in a family’s ability to accept their child’s diagnosis by journey stage

CCF supports on-treatment families to accept their child’s diagnosis

- CCF support is positively correlated with on-treatment families’ emotional acceptance of a diagnosis (b=0.671, p<0.1)
  - 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.
- 50% of on-treatment families believe that CCF has helped them to emotionally accept their child’s diagnosis

Goal 2: Fund research to improve care

Note: Huber Social’s social impact measurement did not include this goal in its approach; however, funding this research project and the results produced contribute to this goal

Goal 3: Provide peer to peer support for families

Peer to Peer Support

Proposed CCF metrics

- Number of families supported by connect groups Number of connect group activities
- Number of other interventions accessed

Huber Social proposes including the following additional metrics from our social impact measurement research:

- Description of connections CCF families have
- Families have healthier relationships
- Families have stronger community connections

1.

CCF Connections

Metrics:

- % of CCF connect services used, by type
- % of supportive relationships, both through CCF and personal

2.

Healthy Relationships

Metrics:

- % change across key program outcomes related to relationships
- % CCF support attributed to relationship factors highly correlated with wellbeing

3.

Community Connections

Metrics:

- % change across key program outcomes related to community
- % CCF support attributed to aspects of community highly correlated with wellbeing

Types of CCF Connections

Key takeaways

- 100% of families connect with other families where their child is receiving (or has received) treatment for their cancer diagnosis
- Almost 3/4 rely on their partner, family or whānau for emotional support during their child’s cancer journey
- COVID-19 is a likely cause of low connection rates among CCF places
  - RMH and Family Places were closed to families
  - Connect Groups were only meeting virtually, if at all

Places CCF Connections Happen

- 12 out of 47 respondents indicated where they connect with other families on a paediatric cancer journey
  - 100% of respondents connect(ed) with other families where their child is receiving treatment
  - 42% connect with others on Facebook or other forms of CCF social media
  - 25% connect with others at RMH or a Family Place
  - 8% connect with others through a Connect Group
  - Other places that families connect are at Women’s Weekend away and staying in touch with families from other respite accommodations

Personal Relationships

- 25 out of 47 respondents indicated which relationships are the greatest source of support for them during their child’s cancer journey
  - 72% cited their partner
  - 72% cited their family or whanau
  - 52% cited friendships created from their child’s cancer journey
  - 8% cited friendships made through local whānau Connect Group
  - 24% indicated other relationships, including friends, staff treating child, and work colleagues

Healthy Relationships

Key Takeaways

- Off-treatment families are able to spend more time with their children and have more supportive relationships compared to new families
- These families also believe CCF has helped them to develop and maintain these relationships
- Enabling new families to spend more time with their partner and supporting them in managing their relationship after a child cancer diagnosis could be priority needs for CCF in the future

Quality of relationships

- Compared to new families, off-treatment families are 24% more likely to have people in their life who help and support them, and 18% more likely to be able to spend quality time with their children ($p<0.01$)
  - 100% of off-treatment families believe that CCF has supported them at least a little bit to have supportive people in their life
  - Over ¾ of off-treatment families believe that CCF has helped them to be able to spend more time with their children

Intimate partner relationships and wellbeing

- Families across all stages of their child’s cancer journey do not get to spend enough time with their partner (4.22 out of 7) and feel that their relationship is somewhat struggling due to the pressures from their child’s cancer diagnosis (3.45 out of 7)
  - For new families in particular, those who feel that CCF helps them to spend more quality time with their partner ($b=0.822$, $p<0.01$) and manage their relationship struggles ($b=0.792$, $p<0.01$) are more likely to have higher wellbeing
  - Less than half (44%) of new families believe that CCF helps them at least a little bit to spend more time with their partner
  - 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
- COVID-19 limited the amount of partner support CCF could provide (i.e. couldn’t fly partners up to hospitals where children were receiving treatment) and limited access to hospitals was a likely stressor

Community Connections

Key Takeaways

- In general, off-treatment families feel the most connected
- Most off-treatment families also attribute this connection largely to CCF support
- COVID-19 may have negatively impacted families' abilities to connect with other caregivers of children undergoing cancer treatment, as well as CCF's ability to facilitate these connections

Connection to Community

- Compared to new families, off-treatment families feel 46% more connected to a community ($p<0.05$)
  - Almost ¾ (71%) of off-treatment families feel that CCF has helped them to connect with a community

Community of Shared Experiences

- As families travel on their cancer journey, they continue to connect with people who understand what they are going through
- Compared to new families, on-treatment families have almost 50% more people in their life who understand how they feel ($p<0.01$)
  - 57% believe that CCF supports them at least a little bit to have these people in their lives
- Compared to new families, off-treatment families have 30% more people in their life who understand how they feel ($p>0.05$)
  - 86% believe that CCF supports them at least a little bit to have these people in their lives

Connection with Other Caregivers

- On-treatment families do not feel that they have opportunity to connect with other caregivers of children with a cancer diagnosis (2.71 out of 7)
  - Only 17% of on-treatment families believe CCF supports them with this
  - COVID-19 may have limited access to other families with children on treatment
- However, off-treatment families are 76% more likely to have the opportunity to talk to other caregivers ($p<0.01$)
  - 79% of off-treatment families believe CCF supports them with this

Qualitative **Feedback**

The following are a small selection of open-ended feedback from CCF survey participants.

Huber Social will share all de-identified feedback from both surveys with CCF.

We will forever cherish and appreciate CCF for the rest of our lives

- *CCF has helped me immensely. Someone to talk to, helpful with things I need to do etc. I'm very grateful for CCF.*
- *Really positive and really kind not overwhelming or in my face but just what I need I think.*
- *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.*
- *They were always there for us. I have met some amazing people who I will know for life.*
- *Impact has been immense. I am here, and my family are stronger together.*

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