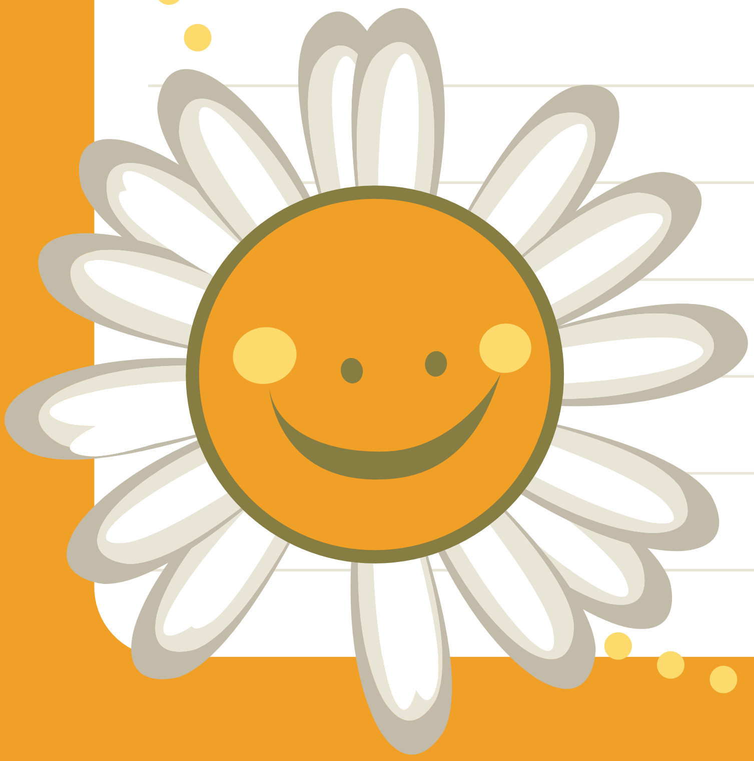
cancer fund
for children

# An Evaluation Report of
# Say their Name
## Residential Bereavement Groupwork
2022-2024



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**NB. Throughout this document the research, literature, measures for evaluation and background are detailed in** black font**. The work of the bereavement groupwork in Cancer Fund for Children is documented in** purple.

# Introduction

Cancer Fund for Children is an organisation that supports children and young people diagnosed with cancer, or living with a parent or sibling who has been diagnosed with cancer. The organisation offers informal therapeutic support to families in their home, in the community, on the hospital ward and at Daisy Lodge in Newcastle, Co. Down. This support is offered from the time of diagnosis, through the trajectory of the illness and through end of life and bereavement support for those who are bereaved. This support extends to a period of three years post bereavement.

This evaluation report relates to the support offered to children and young people who have attended residential bereavement groupwork programmes in the period from 2022 to August 2024. These were held at Cancer Fund for Children's Narnia Log Cabin based on the grounds of Daisy Lodge in Newcastle Co. Down, the charity's therapeutic short break centre. The most recent groupwork sessions were held at the Duncairn Centre, Belfast and Ardaluin House, Newcastle as Narnia was closed for repairs. Over this period, 56 children and young people were offered a place on the programme and 53 children and young people attended. The attrition rate of three is documented in Table 2 Attendance Information below.

In order to evaluate the programme that was offered, it is important to know what current literature tells us about loss and grief in children and young people.

Many authors have addressed the impact of death on families and how it manifests in individuals (Sasser et al. 2019). Factors that influence the impact of bereavement on children include: Support from family and friends, circumstances of the death, communication and openness within the family unit, the caregiving environment, the availability of a primary attachment figure, the school environment and the training of school staff in understanding grief and loss in children and young people and socio-economic status (Azuike et al, 2022; Birgisdottir et al. 2023; Jessop et al. 2022; Revet et al. 2021; Scaefer et al. 2022; Woodward et al.2023; Wray et al. 2022).

Internal factors also impact a child's experience of bereavement. These may include: Their personality, age, age at the time of loss, religious beliefs, developmental stage, overall maturity, previous experience with death and grief, relationship to the deceased person, culture and race/ethnicity and their typical emotional responses and ability to manage change (Birgisdóttir et al. 2023; Revet et al. 2021; Jessop et al. 2022; Wray et al. 2022). These factors are noted in Table1 below:

| INTERNAL FACTORS | EXTERNAL FACTORS |
|---|---|
| AGE | INFORMATION RECEIVED |
| RELATIONSHIP TO DECEASED | PARENTAL RESPONSE TO DEATH |
| DEVELOPMENTAL STAGE | CAUSE OF DEATH |

| | |
|---|---|
| MATURITY | SCHOOL SUPPORT |
| BELIEF SYSTEM | FAMILY COMMUNICATION |
| UNIQUE MEANING OF THE LOSS | ATTITUDES TOWARDS SEEKING HELP |

**Table 1: Internal and External Factors that Influence a Child's Grief**

Others such as Worden (1996), Christ (2000), Dyregrov (1990), Stokes (2004) and Dyregrov and Lytjhe (2024) have addressed the impact of death on children and their responses over the years as they develop to adulthood.

Others highlight the negative outcomes that might arise - such as high vulnerability, mental health problems, increased anxiety, depression and use of illicit substances and personality changes - if these bereaved children receive no support or intervention from the adults in their lives (Dyregrov and Dyregrov, 2012; Ackerman and Stratham 2014; Stikkelbroek et al. 2016; Rosenberg et al, 2015; Foster et al, 2012).

## The Cancer Fund for Children Response

It is a challenge to support families through the life changing experiences of diagnosis, prognosis and death within the family unit. Within Cancer Fund for Children, support is offered through informal and professional interventions on a daily basis, supporting the children and their families through a cancer diagnosis, a later prognosis and, in a number of situations, through the end of life and bereavement of a family member. Post bereavement support is also offered for a further three years beyond the loss of a family member. This includes individual support for children and teens bereaved of a parent or sibling and therapeutic groupwork for children and teens bereaved of a parent, delivered in residential and non-residential settings. These therapeutic sessions bring together the young people, providing a safe space to allow them to remember the one who has died, tell stories about them and listen to the stories of other bereaved children and teens. These therapeutic groupwork programmes facilitate fun through recreational activities but also allow the young people to learn about grief and loss. They aim to normalise the way the young people feel physically, emotionally and cognitively in their grief through psychoeducational modules and discussion. Skills needed to help cope with emotions are learned through creativity and 'serious' fun guided by trained facilitators.

It is quite unique to find an organisation that holds children at the centre of their work. Cancer Fund for Children provides support to a family through their entire journey, from diagnosis through prognosis to post bereavement. It accompanies them through the landscape of serious illness, end of life and bereavement, supporting the children within that family to prevent future complications in their lives. It also aims to empower their parents to be the best support they can be in this time of crisis and loss, while allowing them to grieve themselves. This unique position allows trust to be established between the families and the professionals within the organisation, which empowers families to make the best choices and gain the best support for their individual situations.

# Origins and History

For over 50 years, since 1973, Cancer Fund for Children has supported families impacted by cancer across Northern Ireland. An increasing proportion of support has been offered to bereaved families. Since 2016, bereavement support has been offered to 415 children and young people aged 0-24 years across Northern Ireland. These children and young people were bereaved of either a parent or sibling who died as a result of cancer.

The support offered to these young people has included:

- individual support.
- therapeutic short breaks for bereaved families at Daisy Lodge.
- opportunities to attend relevant events.

Over the years, a number of bespoke bereavement groupwork programmes have been delivered in the community and at Narnia Log Cabin in response to a need identified by the charity's Cancer Support Specialists.

Presently, approximately 25% of referrals received each year become bereaved and are offered bereavement support. Initially this support was offered for a two-year period post bereavement. However, based on feedback from families and staff this has been extended to three years since April 2020.

Contact with parents and carers as stakeholders is an absolutely vital aspect of the support offered to the children. A trust is built with them in the earlier stages of the illness and based on this, we can work together for the best outcomes for the children in their care. When a groupwork programme is beginning, parents / caregivers are contacted to discuss any concerns of the child or themselves about the programme. This allows for clarification about the programme and the themes that will be addressed. We cannot work with children and young people in isolation to their family context.

# A Model for Intervention

Since the 2020 Bereavement Services review within Cancer Fund for Children, the model for the therapeutic support programmes was well examined through various consultations, learning and research. As a result of the Harvard Child Bereavement study (Worden (1996): pp 150-151) three models for children's services after the death of a parent were identified.

These were:

**Model A:** To offer intervention only where children display levels of emotional and behavioural problems or psychological distress.
**Model B:** To offer intervention to those children identified at risk by using a screening measure.
**Model C:** To offer intervention routinely to all bereaved children and their families, recognising that 'a death of a parent is one of the most fundamental losses a child can face.'

Worden highlights the need to identify early those most in need through screening, and to intervene. This approach is the most cost effective and falls into the tradition of preventative mental health.

The Child Bereavement Study reports that a child's self-esteem is not significantly affected initially. However, two years following the death of a parent, self-esteem is significantly lower among bereaved children in comparison to their non-bereaved peers (Silverman and Worden1992). This provides a compelling case for preventive early intervention.

Bereaved children who are offered simple intervention are reported to be more able to talk about their dead parent (Black 1996). The opportunity to 'tell their story', to be heard and to ask questions, even as part of a research process, could be considered an intervention in itself.

# Clinical Objectives

Stokes (2004) states that experience indicates that community-based services which meet the five primary clinical objectives are valued and make sense to the vast majority of families referred to the services she established at Winston's Wish UK. There, they identified five primary clinical objectives for the support work offered. The services were designed to help children and families by providing increased opportunities for:

- **Support, information and education** – supporting children and families to understand death and what it means to them
- **Understanding and expressing grief** – encouraging children and families to share and understand the feelings, thoughts and individual ways of coping with loss

- **Remembering** – helping families to find ways of remembering the person who has died
- **Communication** – encouraging family members to talk openly with each other
- **Meeting others** – providing opportunities to meet other families with similar experiences

Most families need support, not therapy. With support and information, children and young people can be helped to understand what has happened and can slowly learn to live with their loss.

## Cancer Fund for Children Model of Intervention and Philosophy

Within Cancer Fund for Children, Worden's Model C is the chosen means of selection. This model states that intervention should be offered routinely to all bereaved children and their families, recognising that 'a death of a parent is one of the most fundamental losses a child can face.'

Within Cancer Fund for Children, it is recognised that the journey of loss for these children begins at the time of diagnosis of cancer within that family, either in a parent, sibling or for the child themselves. This intervention begins early in the journey and continues to three years post bereavement for those families who have been bereaved. At present, approximately 25% of families referred to Cancer Fund for Children in a given year are bereaved.

Similar to the five principle objectives adopted by Winston's Wish UK, Stokes (2004), Cancer Fund for Children strives to:

- **Support, through information and education,** helping families understand end of life and bereavement and helping them to make choices that are informed and meet their individual family needs.

- Bereavement workshops within the programme equip the young people with a language to **express their grief and their feelings.** This is done through various creative techniques such as art, photography and music. This helps the young people realise that when words are not enough, there are other means of expressing their feelings and grief.

- Sharing stories of who has died and what happened in their particular loss event, allows the young people to understand that it is okay to talk about their loved one and it is healthy **to remember their special person** through the stories they share.

Through the modelling of sharing individual stories by the facilitators, the children and young people learn how to have open, honest conversations about death, the person who has died and their own feelings and reactions to what has happened in their lives. This modelling allows the children and young people to speak openly and trust that it is okay to talk about these topics. Thus, real communication is developed in the groups. Informal coffee morning groups for the parents and carers allow them to also learn how to talk more openly with their children about their loss.

The bereavement groupwork allows the young people to meet others who have known a similar loss and who may understand how they feel. This helps reduce the feeling of isolation and also creates new friendships in their lives.

These principles are in keeping with the new overall model for the Cancer Fund for Children services developed in 2024 as seen in Fig. 1.

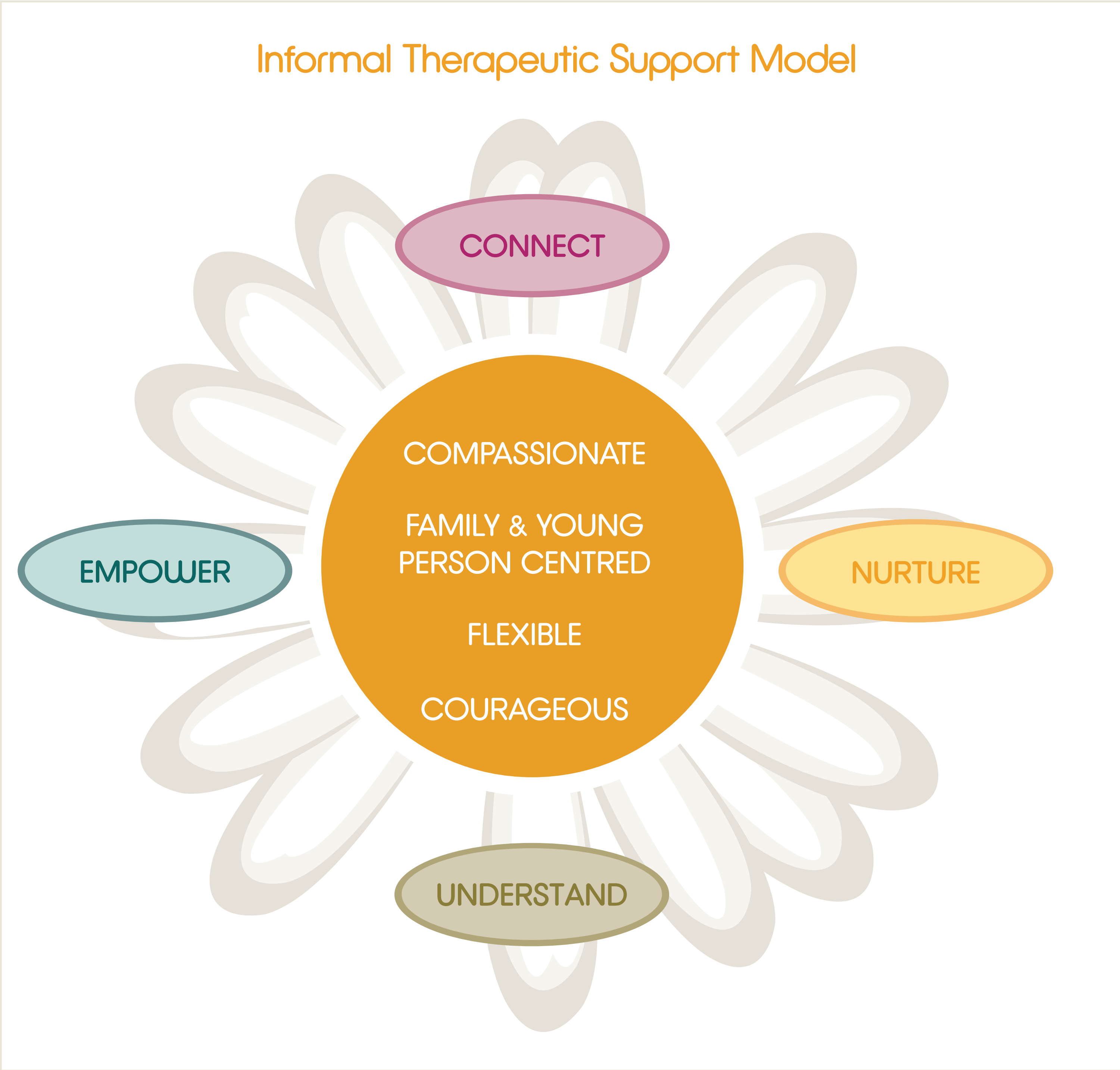


**Fig. 1 Informal Therapeutic Support Model Cancer Fund for Children (2024)**

## CONNECT

- We connect with young people and their families so they can access specific Cancer Fund for Children support e.g. one to one support, group activities, Daisy Lodge and opportunities to connect with others in similar situations
- We connect with young people so they feel heard, understood, less isolated and can access services that will support them
- We connect with families where they are, with compassion and flexibility

## NURTURE

**We deliver support through the development of trusted relationships, nurtured through:**

- Developing a clear understanding of support needs
- Working in ways that are best for each individual/family
- Being there in the reality of cancer day to day
- Helping families to work on relationships within the family unit
- Offering young people and families the opportunity to relate to others in similar situations
- Signposting to other organisations and support
- Providing access to services that seek to nurture family relations

## UNDERSTAND

**We work with young people and families to help them understand:**

- Their own feelings and emotions
- How other family members are feeling/coping
- Ways that might help them to better regulate their emotions
- How to use approaches that might help them to cope better
- How others in similar situations are feeling and coping

## EMPOWER

**We work with young people and families so they may:**

- Feel more relaxed
- Feel able to use practical ways of coping
- Have increased self awareness and confidence
- Feel more able to cope with current circumstances

The organisational approach to practice moving forward is to be **COMPASSIONATE** by offering support with warmth, empathy, kindness and non-judgement.

The work is **FAMILY AND YOUNG PERSON-CENTRED,** promoting choice and autonomy for the young person and their family. Listening ensures that the voice of the young person and their family is at the heart of the support offered.

The work incorporates **FLEXIBILITY,** allowing for a gentle and open approach in responding to families which changes depending on their varied needs. This includes an open culture which welcomes new thinking and approaches.

The individuals working within the organisation are **COURAGEOUS** in ensuring that they provide the best support possible in each unique situation. They understand the impact of cancer and hold space for the difficult conversations and support that may help family members.

The model of practice strives to **CONNECT** with young people and their families so they can access specific Cancer Fund for Children support e.g. individual support, group activities, Daisy lodge short breaks, and opportunities to meet others in similar situations

It aims to **NURTURE** through the delivering of support and the development of trusted relationships. This can be achieved through developing a clear understanding of support needs and working in ways that are best suited for an individual and their family. This helps families to enhance the relationships within their unit and offers young people the opportunity to relate to others in similar situations and signpost them to other organisations and support when necessary. This might involve access to services that can nurture family relationships.

It helps young people and families **UNDERSTAND** their feelings and emotions as well as how other family members are feeling and coping. It teaches them tools and interventions that can help to regulate their feelings. It also helps them to use approaches that can enhance their coping and understand how others in a similar situation might be feeling or coping.

The work strives to **EMPOWER** the young people and their families so that they can feel more relaxed, and use practical ways to enhance their coping. It helps them develop increased self-awareness and confidence.

# Models for Groupwork

Various groupwork models can be found in America (Dougy Centre, Portland Oregan), Australia (Caitlin et al 2023), Germany (Bollig et al, 2024) and the UK (Stokes 2004), primarily run with children facing chronic illness, disability and disadvantage as well as bereavement. Clute and Kobayashi (2013), in their review of peer-reviewed studies on children’s bereavement camps, noted that these camps share the following objectives:

- Providing a safe space for children to share their feelings about their losses.
- Facilitating their grief work.
- Educating them about healthy ways to cope with their grief.

Bachman (2013) highlights that these camps can help children see that they are not alone, can help normalise grief and encourage children to trust their world again through receiving support from others.

The models that underpin these support groups vary across the world. Clute and Kobayashi (2013) highlight the Three Dimensional Grief Model (Ward-Wimmer et al. 2002) (Fig.2 )

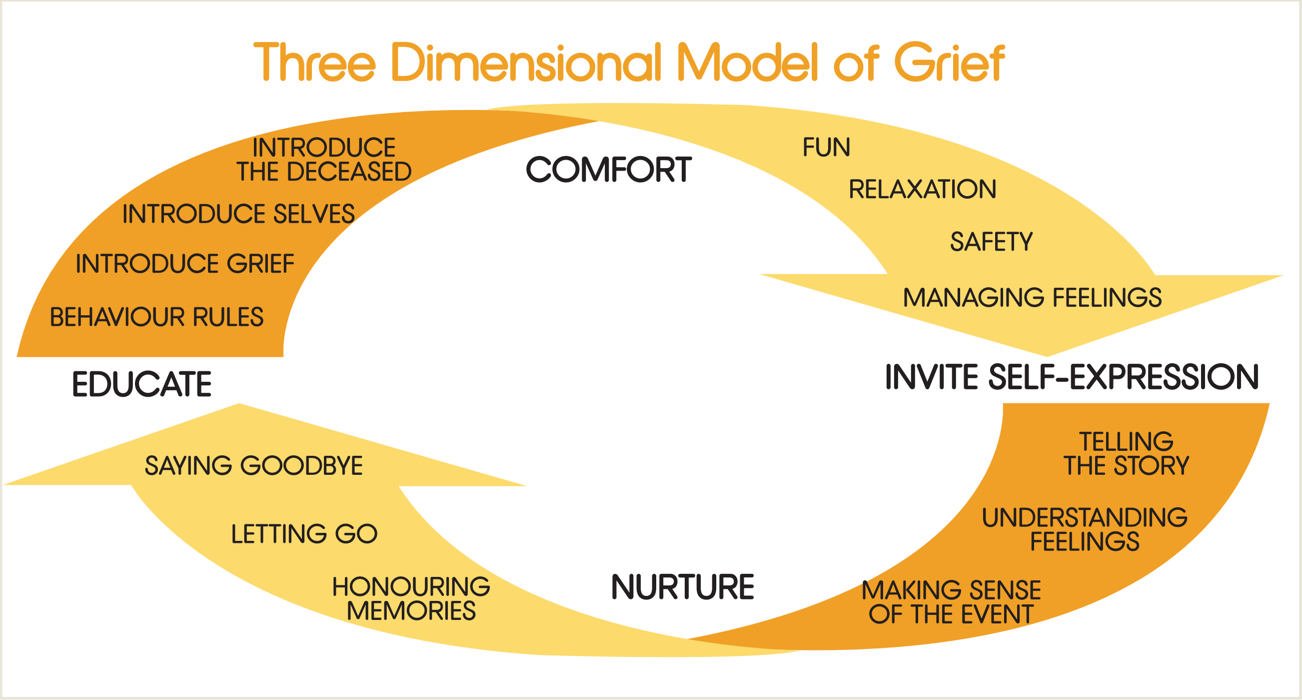


**Fig. 2 The Three-Dimensional Model of Grief (2022)**

*"This practice model is based on the premise that children have to engage and complete their bereavement tasks in order to reconcile, let go off and adjust to their loss."* Zajicek-Farber (2007).

Other models are informed by trauma-informed care principles and aim to help children recognise and respond to the trauma of losing someone close (Mc Clatchey and Raven, 2017). Others promote resilience, such as the positive youth development (PYD) model in the U.S (Richardson et al. 2017). This model aims to develop a child's psychosocial strengths and identifies five areas that characterise development: caring, character, competence, confidence and connection.

The review by Clute and Kobayashi (2013) emphasised the importance of bereavement camps/ workshops having a clearly articulated conceptual model underpinning the structure and activities so that the implementation and evaluation of the groupwork is aligned with the aims.

Within Cancer Fund for Children, bereavement support is offered through informal and professional interventions and a series of residential groupwork sessions for children and teens bereaved of a parent. These sessions bring together the young people, providing a safe space for them to remember the one who has died, tell stories about them and listen to the stories of other bereaved children and teens. These are therapeutic support camps that facilitate fun through recreational activities but allow the young people to learn about grief and loss. They also aim to normalise the way the young people feel physically, emotionally and cognitively in their grief through psychoeducational modules and discussion. Skills needed to help cope with emotions are learned through creativity and 'serious' fun guided by trained facilitators.

This is provided in the comfort of a safe space where time and room is given for self-expression and where sharing is nurtured. The young people are empowered to talk about the person who has died and learn that it is okay to talk about their feelings and the thoughts they have, while exploring the unique meaning this loss has in their lives. The figure below shows the adapted version of the Three-Dimensional Model of Grief Intervention as used within Cancer Fund for Children's bereavement groupwork and includes the heart of the work as that of empowering the children and young people in their journey of loss from diagnosis through post bereavement. Thus, giving them the skills to prevent future pathologies which can arise when interventions and psychoeducation on grief and loss are neglected.

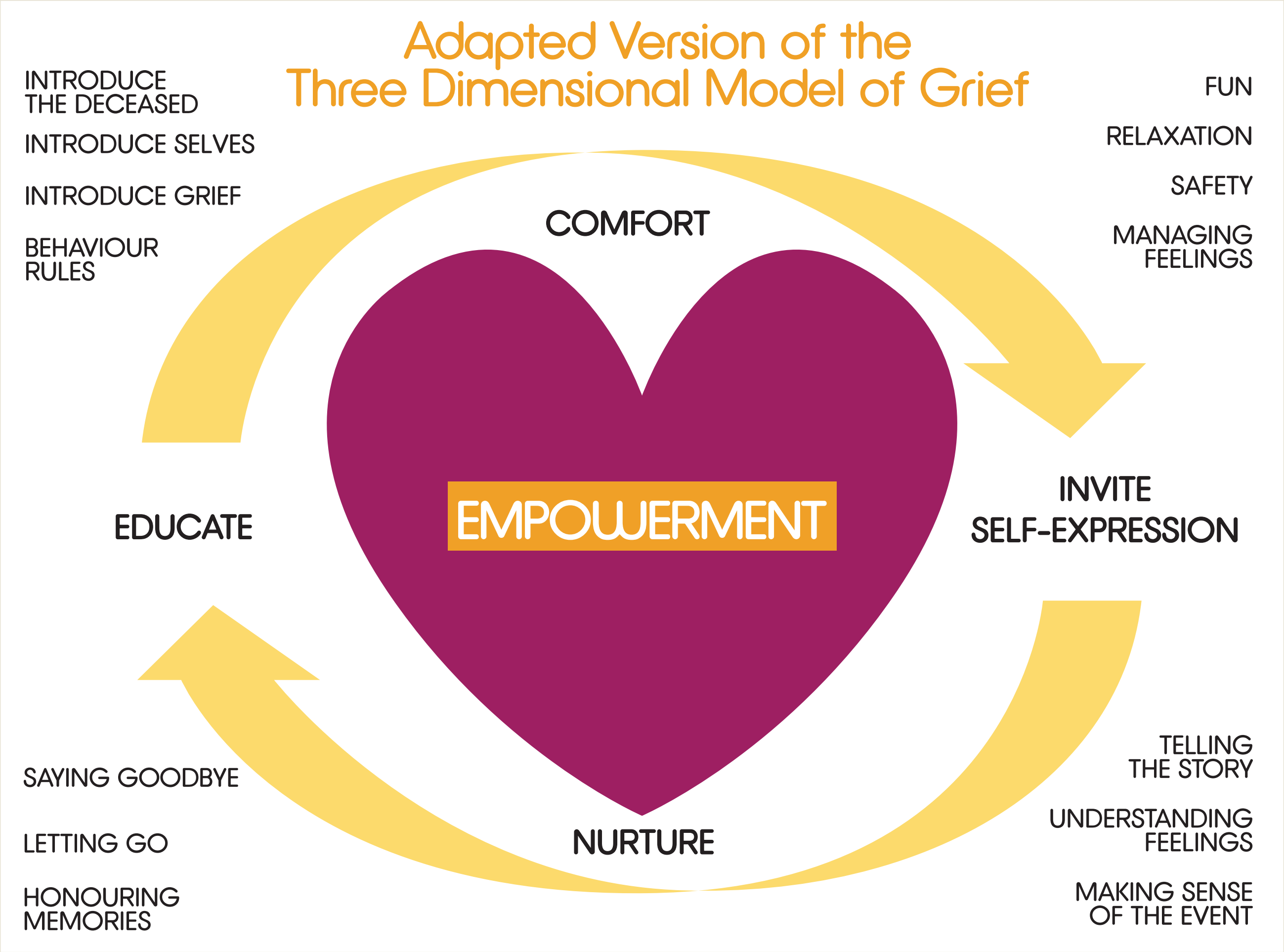


**Fig. 3 Adapted Version of the Three-Dimensional Model of Grief Intervention used in Bereavement Groupwork within Cancer Fund for Children (2024)**

# The Impact of Covid

The following statements from family members highlight the impact that Covid has had on those bereaved within our service.

*"As my wife passed away during lockdown, there was very little support available or offered. My son had been seeing a counsellor who then couldn't come to the house, and he didn't want to speak over the phone, so he hasn't had anything since."*
Bereaved husband

*"Covid has made it more difficult to create space away from the family environment."*

*"Lockdown, homeschooling. Being unable to give my wife the send-off she deserved and meeting up with extended family for support. Lack of face-to-face support groups for both myself and children. Dealing with kids' anxieties and fears,"*
Bereaved husband

*"Grief is horrible and suffocating. It is so permanent and devastating."*

These statements from family members within the care of Cancer Fund for Children reflect the findings of a study: **Covid 19, Time to reflect: learning from bereavement experience of Covid 19** (Easton 2024) conducted by the Irish Hospice Foundation Dublin. A survey of 2,259 respondents provides a pool of knowledge which can be drawn upon to inform future support of those who were bereaved during that period. Awareness of the higher risk for those not supported at that time is important. Health care workers highlighted how difficult it was to watch families go through the lack of rituals and funerals, and also be unable to spend time with their loved one at the end of life. The findings highlight that 86% of the bereaved were negatively affected by Covid 19 with 50% unable to be present at the death.40% felt they could not access the support they required.

The overarching findings indicated that the uptake of support was similar to pre-pandemic statistics. There is a risk of prolonged grief disorder for individuals bereaved at this time, which is worth noting in monitoring individuals within the three-year bereavement support offered by Cancer Fund for Children.

In 2020, all services within Cancer Fund for Children changed and developed in response to the Covid pandemic. This allowed for a total review of the bereavement support offered to families and was led by a working group of specialists from the services team. This review offered an opportunity for staff to fully consider the needs of bereaved families (See Appendix 2). As a result of this review a full time Bereavement Support Specialist role was advertised for Cancer Fund for Children and two half time posts were established. This allowed for gender balance and two members of staff working together to research, train and consult on best practice so that they could ensure the best quality bereavement support within Cancer Fund for Children. Working together, these Bereavement Specialists decided to create three main areas of support:

- Individual support
- Groupwork for children and young people bereaved of a parent
- Coffee mornings for parents whose partner has died in order to empower parents to support their children through grief

In providing support to children, contacting and supporting parents has been a significant and important part of the work,

With regard to the individual support meetings, the following comments by the children and young people speak of the benefits received:

*"The individual support meetings were a really helpful way for me to open up and talk about my feelings. Being able to unload to a stranger especially helped me."*

*"Thanks to this as this past year has progressed, I've become more comfortable talking about my feelings not just here but also with family and friends."*

*"The individual support has been incredibly helpful for me in my grief and I don't know how I could've coped without it."*

The development of a groupwork programme for bereaved children and young people was a key focus of these roles initially. The first of these was piloted in 2022-2023.

Groupwork is a unique opportunity for these bereaved young people to come together with others of a similar age, who have experienced the death of a parent. A safe nurturing environment is provided to facilitate connection, build relationships and reduce feelings of isolation or being different which can result from such profound loss.

A comment from a parent whose children took part, highlights the importance of this work:

*"While it has been emotional with talking about grief, etc. it has been so rewarding with the openness to express and the new friendships made…… I am so grateful that this service is available to the kids, making illness/death, grief not such a taboo subject. Considering when my Mum died almost 28 years ago there was nothing like this, we just didn't talk about it, and you just get on with it. This progress is tremendous."*

## Coffee Mornings for Parents Whose Partner has Died

Contact with parents when organising support for their children highlighted the fact that many of them felt isolated and lonely as solo parents trying to navigate their children's grief.  This led to the offering of an informal gathering for parents to come together for a coffee. This was well attended and has developed into a regular offering for any parent whose partner has died. This has created a growing community of parents navigating a similar loss.

These sessions are attended by both mothers and fathers, who laugh and cry together, support one another and feel less alone. This support continues to grow and develop, demonstrated during Father's Day 2024 when the WhatsApp group for parents was filled with beautiful and poignant photographs, songs and messages of comfort and hope. These mornings have evolved to family summer picnics as well as fundraising events that parents organised themselves. These have also allowed Cancer Fund for Children to offer a grief retreat for bereaved parents who have lost their partners, where they can come  to Daisy Lodge, recharge and learn a little more about their grief journey. The second of these will be held in the coming weeks.

A comment from a bereaved parent noted the following growth for themselves:

*"I met bereaved parents similar ages to myself…. By the end of the first coffee morning, I was already making new friends, sharing experiences and trying to help them with some advice I had received. By the third coffee morning, some of the group had already been fundraising, others planning events…. I felt this group was now the most beneficial group I had attended. We had by this stage formed a meaningful WhatsApp group with a number sharing about books they had read, memory photo walls etc."*

From the summer of 2022 to August 2024 five full programmes have been held either in Narnia Log Cabin or at the Duncairn Centre and Ardaluin House, Newcastle.

# The Evaluation

It is this work, and these bereavement groupwork programmes that are the subject of this evaluation report. Since the work of Cancer Fund for Children is situated within Northern Ireland - coming under the jurisdiction of the United Kingdom and also part of the island of Ireland with a reach that is presently expanding to an all island dimension - it was decided to evaluate the project against best practice guidelines within the United Kingdom and Ireland and consider the best practice models for residential groupwork for bereaved children and young people internationally. This included groupwork run in the United Kingdom, Germany, Australia and the United States and Ireland. It was considered that the work of the bereavement groupwork within Cancer Fund for Children would be measured against:

- The Models of Bereavement Intervention (Worden 1996)
- The primary clinical objectives as set out for Winston's Wish UK (Stokes 2004)
- The Three-Dimensional Model of Grief (Ward -Wimmer et al. 2002)
- The Childhood Bereavement Services Outcome Framework Childhood Bereavement Network UK)
- Serious Illness in the Family Service Questionnaires (SIFSQs) Available from CBN UK for membership use)
- The Irish Childhood Bereavement Care Pyramid (The Irish Childhood Bereavement Network (2014) ICBN Dublin
- The Standards for Supporting Bereaved Children and Young People (2017, 2023) ICBN Dublin
- The theories and models of childhood bereavement that underpin the work of organisations supporting bereaved children and young people

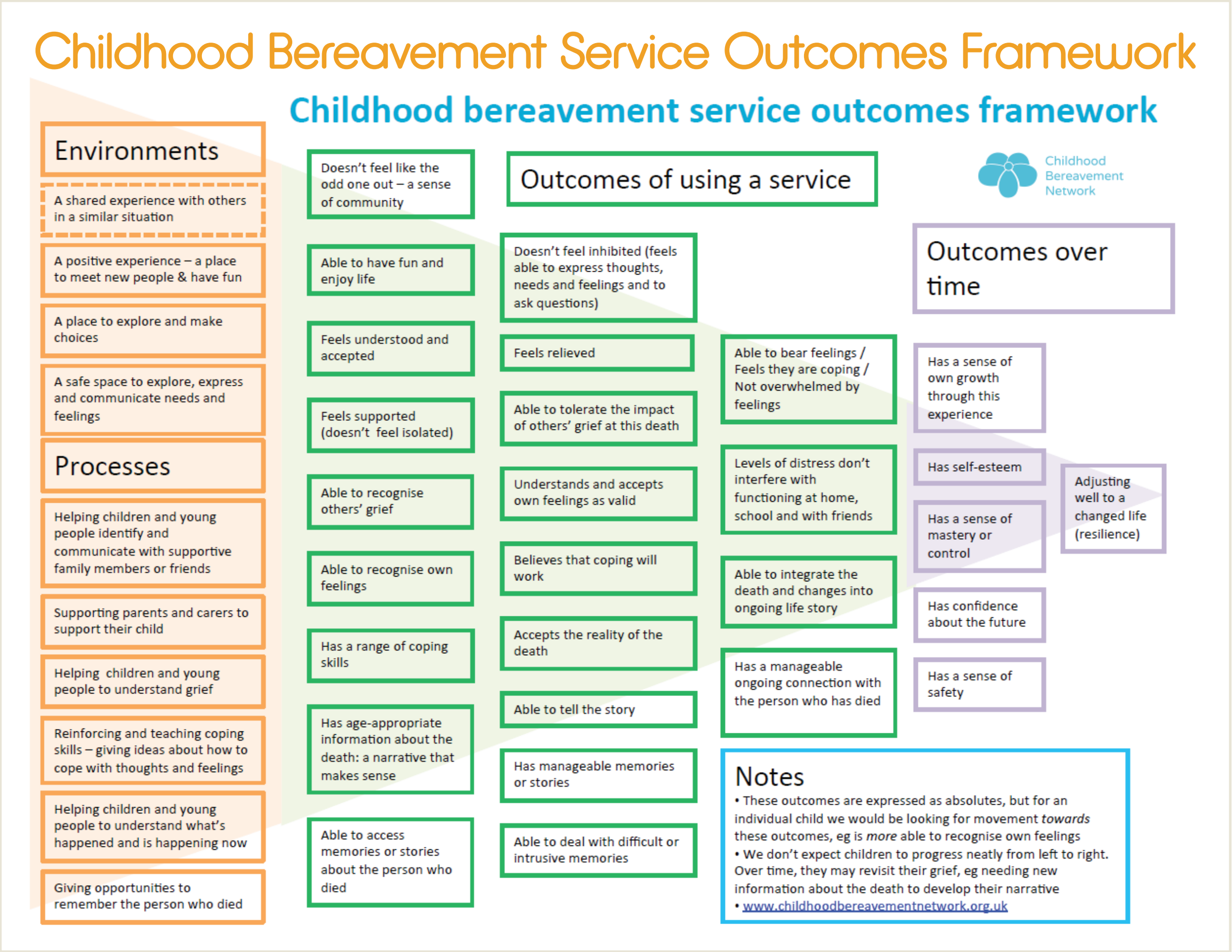
## Research

There is limited research evaluating bereavement groupwork. However, emerging evidence suggests their positive impact. Hartwig and Marlow (2021), reported significant positive effect on self-concept and a reduction in anxiety. Fluegeman et al, (2013), noted that the relationships developed at the groupwork were effective in supporting the children's grieving process. Other studies noted a reduction in traumatic grief and posttraumatic stress symptoms following parental death (Mc Clatchey et al, 2009: Mc Clatchey & Raven,2017) and Salinas, (2021) noted their contribution to post traumatic growth.

Having the proper evaluation tool to measure the outcomes of the support for children and young people before and after the death of someone important to them is vital. In order to adhere to best practice, the work conducted by Alison Penny (2018) referenced in the report on service evaluation: ***Preparing the way*** published by the Childhood Bereavement Network UK (2018) is a clear guide. See Appendix 1 for further detail.

## Childhood Bereavement Service Outcomes Framework

The resulting framework is the Childhood Bereavement Service Outcomes Framework



Childhood Bereavement Service Outcomes Framework

Childhood bereavement service outcomes framework

Childhood Bereavement Network

Environments

A shared experience with others in a similar situation

A positive experience – a place to meet new people & have fun

A place to explore and make choices

A safe space to explore, express and communicate needs and feelings

Processes

Helping children and young people identify and communicate with supportive family members or friends

Supporting parents and carers to support their child

Helping children and young people to understand grief

Reinforcing and teaching coping skills – giving ideas about how to cope with thoughts and feelings

Helping children and young people to understand what's happened and is happening now

Giving opportunities to remember the person who died

Doesn't feel like the odd one out – a sense of community

Able to have fun and enjoy life

Feels understood and accepted

Feels supported (doesn't feel isolated)

Able to recognise others' grief

Able to recognise own feelings

Has a range of coping skills

Has age-appropriate information about the death: a narrative that makes sense

Able to access memories or stories about the person who died

Outcomes of using a service

Doesn't feel inhibited (feels able to express thoughts, needs and feelings and to ask questions)

Feels relieved

Able to tolerate the impact of others' grief at this death

Understands and accepts own feelings as valid

Believes that coping will work

Accepts the reality of the death

Able to tell the story

Has manageable memories or stories

Able to deal with difficult or intrusive memories

Able to bear feelings / Feels they are coping / Not overwhelmed by feelings

Levels of distress don't interfere with functioning at home, school and with friends

Able to integrate the death and changes into ongoing life story

Has a manageable ongoing connection with the person who has died

Outcomes over time

Has a sense of own growth through this experience

Has self-esteem

Has a sense of mastery or control

Has confidence about the future

Has a sense of safety

Adjusting well to a changed life (resilience)

Notes

- These outcomes are expressed as absolutes, but for an individual child we would be looking for movement *towards* these outcomes, eg is *more* able to recognise own feelings
- We don't expect children to progress neatly from left to right. Over time, they may revisit their grief, eg needing new information about the death to develop their narrative
- www.childhoodbereavementnetwork.org.uk

**Fig 4. Childhood Bereavement Service Outcomes Framework CBN UK**
Reproduced with kind permission of the Childhood Bereavement Network at the National Children's Bureau

This framework highlights the environments used with children and young people, the processes undertaken with them, the aimed-for outcomes of using the service and the outcomes over time for the child or young person who has used the service.

## How does the bereavement workshop Cancer Fund for Children model adhere to these outcomes?

### Is it effective?

Measured against the Childhood Bereavement Service Outcomes Framework, the model measures very well. If we break it down into the four key areas of the framework, we can explore this in greater detail:

### Environments:

- A shared experience with others in a similar situation
- A positive experience – a place to meet new people and have fun
- A place to explore and make choices
- A safe space to explore, express and communicate needs and feelings

In the safe space provided within Narnia Log Cabin and the gently paced programme which is flexible to the change in mood of the groups involved, Cancer Fund for Children bereavement support groups provide a safe environment for the children. This is further enhanced by the fact that trust has been built with these children over the period of a parent's illness which makes it easier for them to attend. Time for individual support was also created within the programme for each child to speak with the facilitators about their needs going forward and answer a questionnaire on how it was for them within the group.

The invite letter sent to the children and young people and their families outlines the goals of the group:

- To provide a safe and supportive environment and a shared experience with others
- To provide opportunities to talk about their parent who has died and to remember them
- To help young people understand grief, and to express thoughts and feelings
- To develop coping skills, provide a positive experience and have lots of fun

This helps them understand what to expect on the groupwork programme. Their Cancer Support Specialists will answer any questions for them in advance of the groupwork.

The outcome framework discusses the processes involved and these include:

### Processes:

- Helping children and young people identify and communicate with supportive family members or friends.
- Supporting parents and carers to support their child.
- Helping children and young people to understand grief. Reinforcing and teaching coping skills – giving ideas about how to cope with thoughts and feelings.
- Helping children and young people to understand what has happened and is happening now.
- Giving opportunities to remember the person who died.

Within the Cancer Fund for Children programme, enhancing family communication takes place during the course of the illness and is encouraged through conversation with the Cancer Support Specialist, who can explain what can improve best outcomes for all involved, even at the end of life and in bereavement. These discussions can help alleviate fears and provide opportunities for very special conversations with and about the one who has died. Such exchanges help empower parents and the children in turn. The workshops allow for a new understanding of grief and how it affects the bereaved. Techniques that can help participants cope with their thoughts, mood changes and feelings are explored and practiced. Opportunities are offered for children and young people to remember their deceased parent and share their story with others who quietly witness their telling. These are poignant moments capturing a moment in time when it becomes okay to say their name. This can be life changing and liberating for the young people involved.

Again, the framework discusses the outcomes of using the service:

## Outcomes ofYsing the Service:

- Doesn’t feel like the odd one out – a sense of community
- Able to have fun and enjoy life
- Feels understood and accepted
- Feels supported – doesn’t feel isolated
- Able to recognise others’ grief
- Able to recognise own feelings
- Has a range of coping skills
- Has age-appropriate information about the death: a narrative that makes sense
- Able to access memories or stories about the person who has died
- Doesn’t feel inhibited (feels able to express thoughts, needs and feelings and to ask questions)
- Feels relieved
- Able to tolerate the impact of others’ grief at this death
- Understands and accepts own feelings as valid
- Believes that coping will work
- Accepts the reality of the death
- Able to tell the story
- Has manageable memories or stories
- Able to deal with difficult or intrusive memories
- Able to bear feelings / feel they are coping / not overwhelmed by feelings
- Levels of distress don’t interfere with functioning at home, school and with friends
- Able to integrate the death and changes into ongoing life story
- Has a manageable ongoing connection with the person who has died

Within the groupwork programme the children are encouraged to openly introduce their parent, share a photograph, and say their name. Throughout the time together they can share memories and create items to remember and honour their deceased parent. They explore the grief experience, normalising all the feelings and emotions and the individual journey that each of them are on. They are provided with a range of coping strategies and outlets such as journalling, mindfulness, creativity, memory pieces and physical activity.

Alongside the exploration of grief there are opportunities to create new experiences, memories and friendships that last far beyond the groupwork programme.

### Parental Involvement:

Within Cancer Fund for Children bereavement programmes, parental involvement is essential in attaining good outcomes for the children. A trust is built with them in the earlier stages of the illness, and based on this, we can work together for the best outcomes for the children in their care. When a group is beginning, this involves ‘pre’ phonecalls to discuss any concerns of the child or themselves about the workshop. This allows for clarification about the programme and the themes that will be addressed. Over time, this has developed into a WhatsApp group for the parents of each individual group of young people. This ensures that information about the sessions is shared, so that the parents and caregivers can continue to support their children at home. Parents are encouraged to reach out where needed and follow up phone calls are made to parents/carers after the group has ended. This allows for individual discussion of their child’s needs and offers reassurance about support moving forward. Information is gathered regarding outcomes through a questionnaire which is sent to all parents and carers.

Within the groups in Cancer Fund for Children, it is evident that isolation is reduced.
A young participant stated:

*“I am usually the odd one out, but I am not here, and that feels good.”*

### Outcomes Over Time:

- Has a sense of own growth through this experience
- Has self-esteem
- Has a sense of mastery and control
- Has confidence about the future
- Has a sense of safety
- Adjusting well to a changed life (resilience)

Information regarding outcomes is gathered informally through the parents’ conversations and encounters with the young people. It would be worthwhile to conduct a survey at a later stage to see how these young people are progressing. This might include a section for completion by the parents and by the children and young people who have completed the programme. This would ensure that the voices of the children and young people are heard in relation to their personal progress.

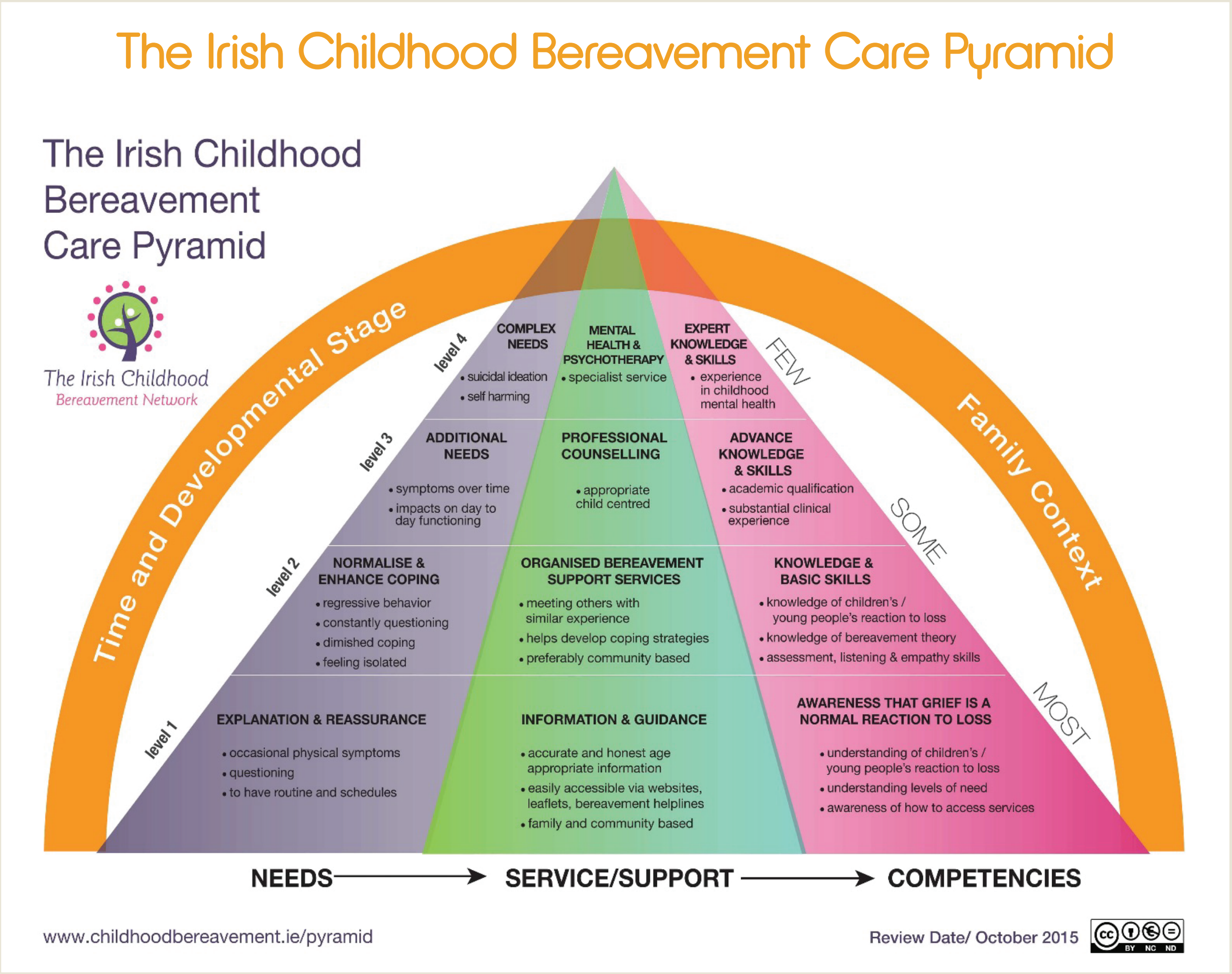


**Fig. 5. The Irish Childhood Bereavement Pyramid (2014)**

The ICBN pyramid and standards set out the overall support structures required to ensure the needs of all children and young people are met, that the services and supports are in place at individual, family, community, regional and national level, and that training and education is readily available to people, providing support at all levels.

They provide a clear evidence base for the adoption of childhood bereavement policy and strategy at national level.

The best bereavement care is that of supporting the adults at Level 1 of the pyramid in supporting their bereaved children and young people. This is done through information and guidance provided by professionals who understand grief and the journey through illness, end-of-life and bereavement.

## In Cancer Fund for Children:

**Level 1 support** is provided to families from diagnosis, through prognosis, through a death and for three years post bereavement. This support empowers the adult members of a family to understand their own grief and understand the difference between their grieving and that of their children and young people. The basic fact is that adult grief is like wading through a river from one side to the other while children's grief is like jumping in puddles. The burden of grief is too heavy for a child to carry for too long and fortunately other things can distract them and allow them to engage with life beyond the loss. Understanding their children's responses and their reactions to a loss is important knowledge for a parent. As is the ability to recognise if their child is having difficulty with their loss, which will allow them to seek the appropriate support required.

This psychoeducation is provided through information and guidance shared by the Cancer Support Specialists to all families referred to the organisation.

**At Level 2** parents and children meet others with similar experiences which decreases their isolation, helps them develop coping strategies and is based within the safe community of the organisation. This facilitates peer support which is directed and guided by professionals through residential and non-residential workshops. These include psychoeducation on the experience of grief and loss, creative exercises to help young people share their stories and activities which introduce them to coping methods and help develop their self-esteem and resilience.

**At Level 3** support is offered to any parent or child who is assessed as having individual difficulties and may benefit from individual support. Examples of these would be:

- A child who has become anxious since the loss
- A child who might be stuck in an aspect of the illness or death
- A child who might be self-blaming because they misbehaved before their loss
- A child dealing with unfinished business or feels something was left unsaid

**At Level 4** Referral to Level 4 support may occur in a few cases where a parent or child or young person requires specialist support for mental health, addiction or neurodiversity needs beyond the scope of the organisation's support team.

**Standards for supporting Bereaved Children and Young People**
**ICBN Dublin 2nd edition (2023)**
Link: *https://www.childhoodbereavement.ie/wp-content/uploads/2023/11/Standards.png*

Standards for supporting
Bereaved Children & Young People

Standards for supporting Bereaved Children & Young People

A FRAMEWORK FOR DEVELOPMENT

Second Edition, 2023

DEVELOPED BY
The Irish Childhood Bereavement Network

proudly supported by TUSLA Irish Hospice Foundation

**Fig. 6 Standards for supporting Bereaved Children and Young People (2023)**

The original standards document was created by the Irish Childhood Bereavement Network in 2017 as a gold standard that is needed to provide the best support to bereaved children. The second edition was updated after 5 years after consultation with key stakeholders in Ireland. It was also informed by the findings of the Childhood Bereavement Services National Survey 2023, which was designed and deployed by the ICBN.

## The Standards

**Standard 1 Child & Young Person:** Children's experience of bereavement will be recognised, acknowledged and supported in accordance with their needs over time.
**Standard 2 Family:** The family is generally the main source of care for the bereaved child and will require access to reassurance, information, guidance and support to provide this care.
**Standard 3 Local Community:** All bereaved children should have access to bereavement information, guidance and support services in their local community as required.
**Standard 4 Service Providers:** All service providers will ensure that governance, procedures and protocols are in place to ensure ethical, safe and appropriate bereavement service delivery to the children in their care.
**Standard 5 National:** National policy and local infrastructure includes appropriate responses to, and integrates the needs of bereaved children.

In Cancer Fund for Children, these standards were considered in the planning of the bereavement services and the groupwork for children since 2020. They have informed the education and training of the professionals who support these programmes. They have helped in the empowering of bereaved families, schools and communities to promote resilience and provide support for the bereaved children in their care. They can also shape future investment in bereavement care and help in the development of funding applications.

The standards have also helped in the development of confidence in the service provision offered through information, support, and services being offered to the bereaved children, young people and their families. It has helped the service to provide support based on the latest international findings in the field of children's bereavement care. The standards have helped all those involved in the support of the bereaved child to understand their competencies and to recognise when they require complementary supports. They have allowed for strong and transparent governance through self-assessment. This ensures that the bereaved child and their families are central to the support provided and are appropriately supported. It allows for best international standards to be adhered to by the service providers. It highlights the need for the voice of the bereaved children to be heard and in time integrated into national policies related to children.

These standards can allow Cancer Fund for Children to continue quality review of their practices into the future. This will allow for the development of their services in light of identified evolving needs of bereaved children in their care.

# Bereavement Theories that Underpin the Support of Children and Young People

While it is essential that health professionals supporting the bereaved should have a sound knowledge of the theories and models of grief and loss, it is important to note that the key theories underpinning children's and young people's grief are:

- Continuing Bonds Theory (Klass, Silverman and Nickman (1996)
- Dual Process Model DPM (Stroebe and Schut (1999)
- Narrative Therapy (Neimeyer 2012)

## Continuing Bonds

Continuing Bonds introduced a paradigm shift in which those supporting the bereaved began to help bereaved people to establish and strengthen their ongoing attachment to the deceased. Ancestor worship in many cultures such as Asian society, and the Mexican tradition of the Day of the Dead (Diá de los Muertos), which we see highlighted in the Disney animation Coco is an example of the ongoing role that the dead continue to play in a family and society. Practices such as keeping mementos and photographs, having mental conversations, and carrying out rituals to mark anniversaries and other special dates are all examples of establishing a continuing bond. Parkes (2006, p.34.) explained it as follows:

*"The recognition of this continuing bond with the dead is one of the things that makes it possible to let go of the person "out there" simply because we realise, we never lost them "in here".*

In the Harvard Child Bereavement study (1987) Worden and Silverman discovered the strength of the children's continuing connection to the deceased parent was an unexpected finding. They stayed connected through dreams and through talking to, or thinking about the parent.

The findings of this study brought about a paradigm shift in grief counselling from the early 1990s onwards. Previous thinking was that it was important to help the bereaved sever ties to the deceased. Now the maintenance of a continuing bond is seen to be beneficial.

Instead of helping children to 'recover' and find 'closure' the new aim was to honour the deceased parent and recognise that the parent will have a continuing psychological presence in the child's life as they develop. The study concluded that children find comfort and solace from constructing and remembering a relationship with someone who has died, whether that person is a parent, sibling or friend. Silverman (2000) suggests that this can be done through keeping a diary, talking about the person with others, and even choosing a career in a helping profession to keep the memory alive. One child interviewed by Silverman expressed it as follows:

*"It is never really over ...... she is never really gone. In life and in death, she is so much part of who I have become. A piece of her will live on. And a piece of me will always be missing."*
Child in Silverman (2000) p.185

A word of caution from Parkes (2015, p.76) states:

*"A continuing bond can be constructive if it enables people to enjoy and make use of their memories of their time together, but it can also be problematic if, for instance, they see it as their sacred duty to grieve forever as a tribute to a dead partner or child."*

Worden (2009) notes that since anxious attachments sometimes lead to chronic grief, he feels that the concept should not be applied to everyone.
Continuing bonds arose from the attachment theory of Bowlby which shows us that the purpose of grieving is not necessarily to sever the bonds with the dead, but to rework the bonds in a way that the deceased can remain part of the survivor's inner and social worlds.

## Dual Process Model

The dual process model or oscillation model was developed from the research of Stroebe and Schut (1999). The model acknowledges a range of responses to loss and bereavement. In this model they identify two types of stressors, known as loss orientation and restoration orientation. The regulating process between these two stressors is called oscillation. Confrontation with the loss and avoidance of emotionally charged reminiscence is interspersed with attendance to practical matters such as financial changes or household tasks.

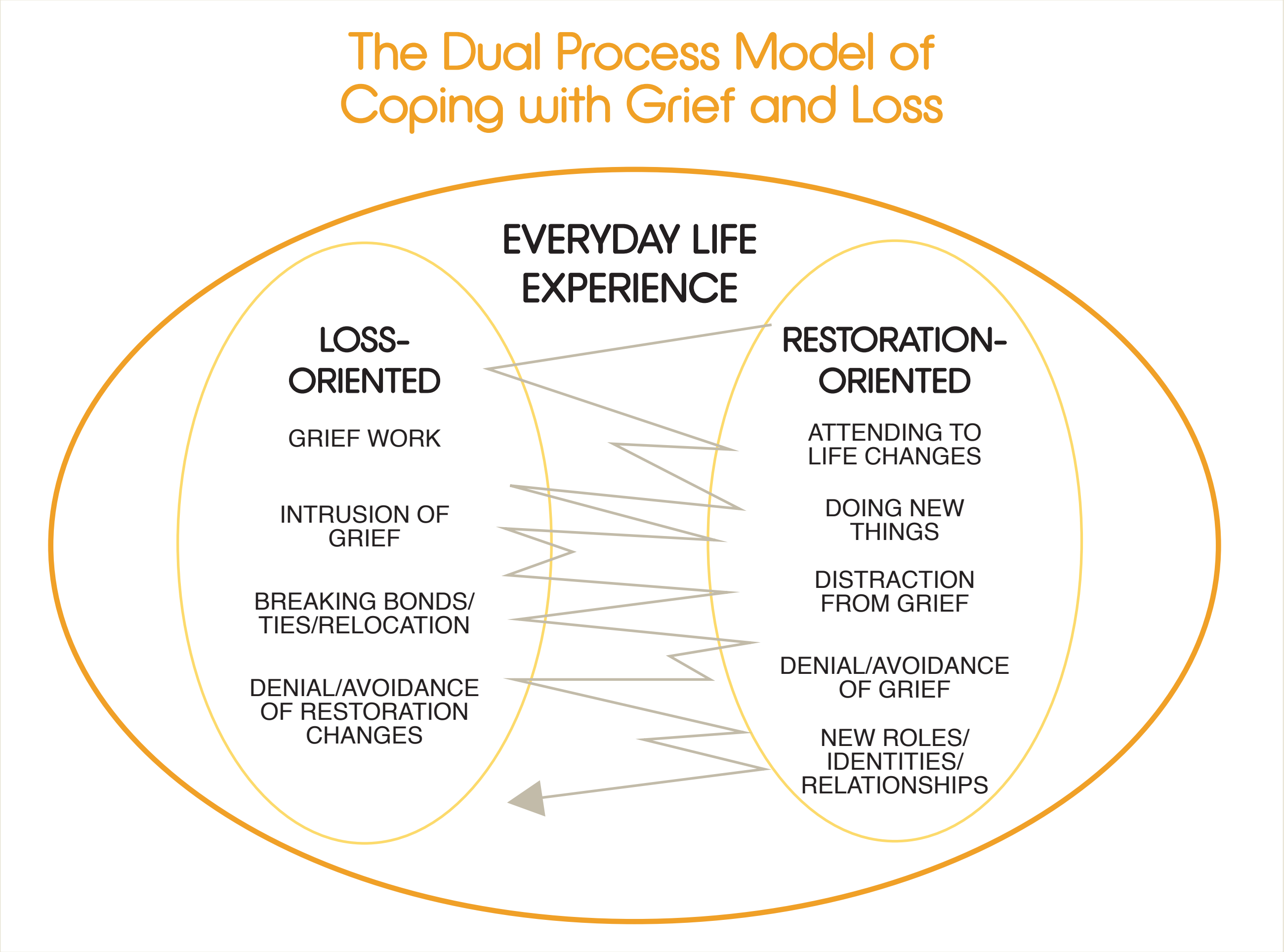


**Fig. 7: The Dual Process Model of Coping with Grief and Loss**

In layman's terms, this model allows the bereaved person to learn to manage their grief as well as managing the tasks related to everyday living.

For children and young people Julie Stokes (2021) describes it as the challenge of holding on and letting go. She illustrates it as being on a grief swing. On this swing, a person swings between the land of loss - where they can relax and simply sob, get furious and scream or just sit with their loss and think quietly about the person who has died.

Conversely, in the land of rebuilding they might want to clear out some of the person's things to make room to rebuild their own life. This is the side of grief where a young person can set goals and follow new interests or accept new people into their family. A young person may find themselves swinging forward and back in their grief several times in the same day. In time they can learn to manage their feelings of loss together with building their own life as it moves forward. They learn to live with the rhythm of grief as it ebbs and flows like the sea or rises and sets like the sun. They come to understand that grief too has a natural rhythm.

## The Holding On and Letting Go Model

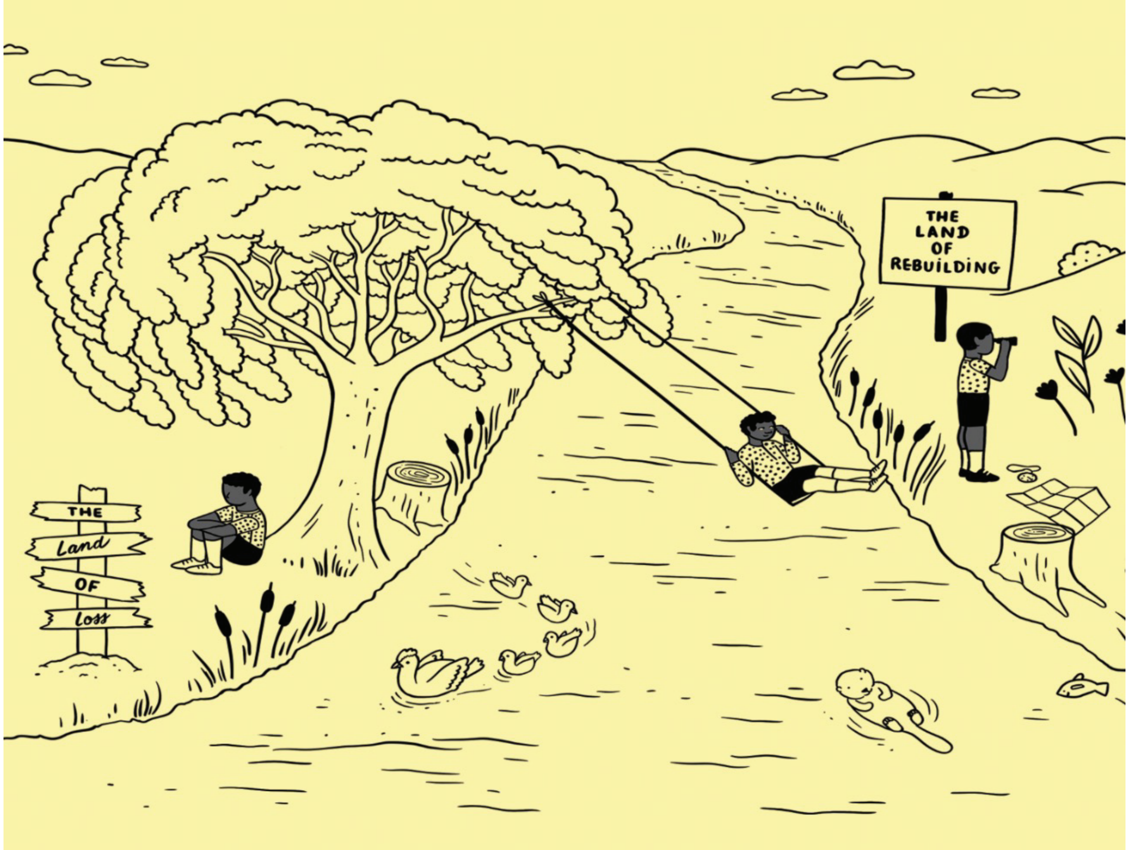


**Fig. 8: The Holding On and Letting Go Model Julie Stokes (2021)**

This illustration allows children and young people to normalise the way their feelings, behaviours and thoughts change constantly following the loss of someone important in their life. It can help them map exactly where they are in any given day with their grief. It helps them realise that they are not going mad. This model can really open up discussion about the multiples that inhabit our grief at a physical, cognitive, emotional, behavioural, spiritual and social level, taking away the fear and isolation an individual might feel.

## Narrative Therapy

Narrative therapy maintains that *“people make meaning in their lives based on the stories they live”* (Ricks et al., 2014, p. 100).

When we are bereaved, the life we have lived to date gets shattered, and fragmented. It’s like a jigsaw falling to pieces on the ground. In moving forward, we need to rebuild a new story, taking the best bits of the old one and finding new meaning and new pieces to create a future story. Rebuilding these stories takes time and can be done best when shared with others who can witness our stories and allow us the acknowledgement of who and what we have lost, who we are now and how we have adjusted to this loss.

Our grief narratives include the story of:

- What caused our special person to die
- Who that person was in our lives
- The relationship we had with them
- The legacy they have left us in terms of what we learned from them, how they lived life and illness etc.

In time we can tell the story of how we adjusted to this loss. These stories can be expressed in any medium.

- Christ (2000) states that: *"It is increasingly apparent that the concept of detachment, ridding oneself of emotional ties to the dead, does not describe the course of mourning for children. We are beginning to understand how a child's relationship with the dead parent changes as the child matures."*

These legacies of the dead parent were created through the incorporation of the child's own memories, experiences, wishes and fantasies, added to by those of their siblings and surviving parents as well as the stories shared by those in their community about the deceased.

Within Cancer Fund for Children bereavement support, the theories and models that underpin children and young people's grief following the death of a parent or sibling are closely adhered to in their work. Those facilitating the programme have been trained in bereavement and loss and understand the nuances involved in the grief of a child who has lost a parent and how that differs from a sibling who has lost a brother or sister. They have a clear understanding of the influences of grief on an individual and the factors that contribute to the difference in coping with loss even within individuals within the same family. The team are constantly informing themselves of new developments in thinking and intervention with bereaved children through reading and attending various workshops and conferences with an international dimension.

# Holding Space

Holding space for a group of bereaved young people and children carries huge responsibility for the facilitators involved. Allowing these young people to feel safe enough to share the depths of their grief with others and be witnessed and acknowledged in their sharing, holds a great obligation for the adults involved. So often, this is not recognised within caring organisations or addressed in the debriefing that follows such sessions.

In order to find out what it is like for those who facilitate the Cancer Fund for Children bereavement programme, they were asked to participate in a reflective exercise which brought them through a programme which had been recently facilitated. They were then asked to free-flow write about the experience using their right brain to relate to the experience rather than logical thought.

## The reflections below:

*"There is a great sense of responsibility I feel when supporting a group of bereaved young people. The responsibility to do them, their parents and the person they are remembering the justice in providing an intentional therapeutic space to discover, educate, understand and process some of their grief.*

*I feel a sense of nervousness before every new group. The unknown of what they are expecting and how they will respond to me as a staff member and also the need to create the right space for them to feel safe, make friends and share their experience. As a staff member, entering into the session with 12 young people each holding photos of a parent who sadly has died, alongside colleagues holding photographs of a loved one and myself with an image of my best friend 'Griff' there are many emotions before, during and after. I feel privileged to be able to 'hold the space' in a way that I struggle to see being done outside of this group. A sense of sadness, nervousness and regret fill me knowing I will soon introduce my loss but also because I can see the anticipation on the faces of the others, the tears, some heads down and others just staring at their photo.*

*Then the sharing begins, and with each new voice comes another person to the group. We get to hear how much these parents are loved and missed, the best memories in the smallest of things and a connection as a group is being formed that will not be broken. These young people whether 8 or 17 have courage, strength and compassion. They feel less alone and for a short while they feel normal. This is what gives me the greatest sense of achievement, and a feeling of – this is an important moment for everyone here today.*

*I am thankful to feel safe, listened to and valued in this work by colleagues and I hope the young people feel the same."*

Joe

*"A huge responsibility, that I really wanted to 'get right', to safely hold the hearts of these children as they trust us…..such an awareness of the weight of heartbreak, loss, longing for their mum or dad, alongside moments of utter childhood innocence and raw emotion. For some, not having the words to express their pain, trying to comprehend the enormity of mummy or daddy being gone, alongside the most precious moments of laughter, freedom from the heaviness, ability to just play, just be, even for a short while.*

*Little eyes that have seen so much and continue to carry so much worry, their world changed forever – being able to unfold a little photograph from a back pocket to show a room of others their age, or for others a large photo in a frame, willing themselves, taking a breath, before turning it around…. "This is my mummy, she died…."*

*To see each candle in a jar decorated with childish depictions of precious memories, what an utter, indescribable honour to bear witness.*

*A child in daddy’s t-shirt, a child with mummy’s fingerprint on a precious necklace, such poignancy and as a mother at times too unbearably painful to allow my mind to wander too far into the unimaginable, only to know what I would hope for my children if I was no longer here, and to offer everything I can while they are on such a courageous journey with us.*

*Moments of realising they are so young, babies, holding them in my heart…..”*

Gemma

# Attendance Information

### Who has been supported to date?

| GROUPS | TIMEFRAME | AGE GROUP | FORMAT | VENUE | NOS. |
|---|---|---|---|---|---|
| 1 | Summer 2022<br>July - October | 8 - 11 yrs | 1 Community Day<br>3 Residentials | Narnia | 10 |
| 2 | November 2022 - May 2023 | 12 -14 yrs<br>15 -17 yrs | 1 Community Day<br>3 Residentials | Narnia | 8<br>6 |
| 3 | Summer 2023<br>Day Programme | 8 - 11 yrs | 4 days over 2 weeks (Tue & Thu) | Narnia | 10 |
| 4 | February - May 2024 | 12 -17 yrs | Community Day<br>3 Residentials | Narnia | 12 |
| 5 | August 2024 | 8 - 11 yrs | 5 days | Duncairn<br>Ardilaun | 11 |
|  |  |  |  | TOTAL | 53 |

**Table: 2 Attendance Information**

**Attrition rate:** The programme was offered to **56 bereaved children** in all. Three children did not attend due to various reasons including: anxiety stating that the programme was not for them and one young person whose behaviour on the community day indicated that the facilitators had a fear of keeping him safe in the group. All of these three children and young people received individual support for their personal needs outside of the group.

To date, the programme has only been offered to children and young people who have been **bereaved of a parent.** All groups are by invitation only and are closed groups for the duration of the programme.

What's in a name? The name given to a group is a very important defining aspect for those who take part. The name now given to these residential groupwork programmes for bereaved children and young adults is #SaytheirName. This name came from much discussion held in the teenage group in the period between November 2022 and May 2023. The facilitators encouraged a dialogue on what the name might be and after a number of suggestions and quite a lot of dark humour one young person suggested #SaytheirName. This was quickly agreed by all and is now the logo for all the bereavement groups held within Cancer Fund for Children as seen below:

#SaytheirName Logo

**Fig. 9: # SaytheirName logo for groups within Cancer Fund for Children**

The rationale for the name came from the fact that the teens quickly learned within these groups that it was okay to say the name of the person who has died within their families. This is not an easy thing for bereaved teenagers to do following a death and it is important that they are given permission that it is okay. This realisation was liberating for the teens involved and is a core teaching within the groups.

# Discussion

## Support Offered

Cancer Fund for Children is in the unique position of supporting children – who are held at the core of their work- and their families from cancer diagnosis, through prognosis to post bereavement.  In this, they accompany the families through the landscape of serious illness, end of life and bereavement. This bereavement support is offered for three years post bereavement. In recent years, approximately 25% of referrals to the service annually are bereaved.

This outreach allows a trust to build between the Cancer Support Specialists and the families whom they support in their homes, in the community, in Daisy Lodge and in hospital settings. It allows for a coming together alongside the person who is diagnosed, their families and their children at an extremely stressful time in their lives. This support empowers the families to have the difficult conversations needed to make the best decisions for their unique family unit. Support is offered through individual intervention, or through groupwork in a series of residential and non-residential programmes for children and young people bereaved of a parent. Informal support is offered to parents through coffee mornings, WhatsApp groups and an annual grief retreat.

## Residential Workshops

These are therapeutic support programmes held in Narnia Log Cabin at Daisy Lodge over a number of weekends, for the older age group and over a series of days for the younger cohort. They are facilitated by two Bereavement Support Specialists who share the role and have developed and planned each programme from the initial pilots to the evolving workshops based on the feedback and learning gained from each group. These facilitators are supported by staff members who help with the activities involved.

## Model of Intervention

In keeping with the work of Worden (1996), Cancer Fund for Children offers intervention routinely to all bereaved children and their families, recognising that *'a death of a parent is one of the most fundamental losses a child can face.'*

Similar to the five principle clinical objectives - adopted by Winston's Wish UK (Stokes 2004), the bereaved support offered includes support, information and education. It equips the children and young people with a language to express their grief and their feelings through any medium they desire. It gives them a safe space to remember the parent who has died and share their special stories with others who understand and witness the telling. Through the modelling of the facilitators, the young people learn that it is okay to communicate their feelings and thoughts about their loss and what it means to them. Meeting others who *'get it'* reduces their feelings of isolation and allows them to develop new friendships in their lives. These objectives tie into the new Informal Therapeutic Support Model of the organisation developed in recent months. The model strives to connect, nurture, understand and empower the children and families in their care through compassion, flexibility and courage.

## The Model for the Bereavement Support Workshops

In planning the residential workshops, various international work was researched. In evaluating the Cancer Fund for Children model it was found that it compares closely with the Three-Dimensional Model of Grief Intervention used at the Wendt Centre Bereavement Camps in the USA. This model notes that within a safe space, children and young people are invited to express themselves and receive psychoeducation on grief and how it can affect their responses and coping.

An adapted version of this model (Fig.3) indicates that Cancer Fund for Children bereavement support holds at its core, the empowerment of children and their natural support networks of parents, family and community through support, psychoeducation on grief and loss and developing awareness of children's grief.

The Cancer Fund for Children residential programme for the children and young people is provided in the comfort of Narnia Log Cabin, where time and room is given for self-expression, where sharing is nurtured, and the young people are empowered to talk about the person who has died. They learn that it is okay to talk about how the feelings and the thoughts they have while exploring the unique meaning this loss has for them in their lives. This is offered in an age-appropriate way depending on the age of the group participants.

## The Impact of Covid

In 2020, all services within Cancer Fund for Children changed in response to the pandemic. This allowed for a full review of bereavement services within the organisation. This in turn, led to the development of a Bereavement Support Specialist role. This is a shared role which has the benefit of including both a male and female perspective. Together, these individuals developed their role through consultation, research, and training. They have developed their bereavement programmes for the workshops and planned the themes and format. Pilots of this programme took place in 2022 with 8–11-year-olds, and 12-14-, and 15–17-year-olds run in parallel. As a result, some adjustments occurred based on the learning and feedback from those sessions. This included changing the programme for the younger children from a residential to a non-residential format. The programme that is offered is well informed and based on international best practice.

## The Evaluation

The evaluation of the bereavement support programme within Cancer Fund for Children was measured against best practice criteria for bereaved children's services as laid out by the Child Bereavement Network UK in the Childhood Bereavement Services Outcome Framework CBN UK and the Childhood Bereavement Pyramid of the ICBN Dublin, and the Standards for Supporting Bereaved Children and Young People ICBN Dublin.

Penny (2018) service evaluation report is a clear tool to measure how the service is operating. Measured against the Childhood Bereavement Service Outcomes Framework, Cancer Fund for Children bereavement services score highly.

The environment of Narnia is conducive to safety and comfort and is an amazing setting with a warm ambience for these workshops. The skill, the knowledge and the warmth as well as the innate ability of the facilitators and staff ensures sharing can take place with ease. The processes that involve fun and creativity lend a richness to the work and allows for gems of sharing to emerge.

The reduction in isolation and the friendships formed through the groups as well as the opening of communication lends itself to favourable outcomes and the services can measure highly against the outcomes of using the service indicators of the framework document.

While a questionnaire is used with the children at the initial Community Day of their programme and at the end of the workshops, it was deemed that this was intimate to the work of the group members and confidential to them. Therefore, it was not used as part of the evaluation.

The involvement of parents/carers as stakeholders in the outcome of their children’s grief journey is essential. They are great monitors of their children’s progress over time and of any difficulties that may emerge.

Their involvement over time, led to the unexpected consequence of having a very strong parental peer support community through the forming of a WhatsApp group and informal coffee mornings.

With regard to outcomes over time, while this information is gathered informally through the parents’ conversations and encounters with the young people it could be worthwhile to conduct a survey at a later stage to see how these young people are progressing.

### The Bereavement Care Pyramid and Standards for Supporting Bereaved Children and Young People ICBN Dublin

The bereavement support service within Cancer Fund for Children provides support at Level 1 of the bereavement care pyramid through information and guidance which empowers families and their children on their journey through grief. The groupwork and informal parental gatherings offer Level 2 support through peer support led by professionals.

The individual support offered through bereavement is at Level 3 of the pyramid and requires an understanding of the nuances involved in children and young people’s grief. This allows the team to help the child become unstuck in the issues that are causing them problems and allows them to move forward in their grieving process.

Referral to Level 4 support is offered when the support needed goes beyond the competencies of the Cancer Fund for Children staff. Collaboration with outside agencies ensures this follow up takes place smoothly and efficiently. This need can arise because of mental health issues, addiction, neurodiversity, identity issues, eating disorders or learning needs.

The Standards for Supporting Bereaved Children and Young people was considered in planning and developing the bereavement programme, and the interventions used. They have informed the education and training elements of the programme. They have helped in the empowering of bereaved families through information and guidance. They have helped in promoting resilience in the bereaved children through collaboration in their care within schools and other agencies. They can help shape future investment in bereavement care and help in the development of funding applications.

Confidence in the service provision has grown over the past few years and can continue based on evaluation and review. The preventative nature of the work makes it economically effective in the prevention of future pathologies. The standards can ensure that service development takes place while considering evolving needs of bereaved children into the future.

## Bereavement Theories that Underpin the Work

Within Cancer Fund for Children's bereavement support team, the theories and models that underpin children and young peoples' grief following the death of a parent or sibling are closely adhered to in their work. Those facilitating the programme have been trained in bereavement and loss and understand the nuances involved in the grief of a child who has lost a parent and how that differs from a sibling who has lost a brother or sister. They have a clear understanding of the influences of grief on an individual and the factors that contribute to the difference in coping with loss even within individuals within the same family. The team are constantly informing themselves of new developments in thinking and intervention with bereaved children through reading and attending various workshops and conferences with an international dimension.

# Conclusion

The bereavement support service within Cancer Fund for Children is a vibrant growing service that has proven its worth since its enhancement in 2022. Set in a broader service that has built trust with the families who are experiencing serious illness through cancer diagnosis, the service is in the unique position of coming alongside at a time of major stress and upheaval and providing the best support available for each family and their unique needs.

The warm informal approach of meeting these families - often in their homes - allows for a trusting relationship to be built, which allows open dialogue around difficult issues and allows for a depth of conversation to be achieved.

The defining features of this support and why it works are the fact that all deaths are cancer related. The children and parents are met in advance of the support programme and during the period of the illness. There is family involvement in the process. The nature of activities in the workshops and the dynamics of each group varies every time. The non-intrusive sharing around the campfire. The encouragement of each child's gifts e.g. the kindness one offers another when upset. The development of a more confident child from this very special experience.

# Recommendations

## Internal Recommendations

- The organisation should consider taking the learning from this work and extend it to those young people who have been bereaved of a sibling. Consideration will need to be given to the unique elements of this demographic of young people.

- This report highlights the clear advantage and benefits of having a consistent staff team, as key contributors in establishing trust and rapport. This is aligned with Cancer Fund for Children's 'informal therapeutic support model' and where possible should be applied across Cancer Fund for Children programmes.

- All staff across Cancer Fund for Children should be trained to a collective and agreed level of training, specific to bereavement and loss and how it impacts children, adolescents and their families. The management team should agree and communicate this level.

- The management team should give thought to how they widen the experience level across the team to ensure appropriate introduction/familiarisation onto programmes and strengthen the organisation's resilience in delivering this work.

- The organisation would benefit from carrying out a mid – longer term survey/engagement with participants to better assess longer term impact. This is an exercise that would be beneficial across all of Cancer Fund for Children's work.

- The organisation should ensure the voice of young people is sought throughout, including assessing the effectiveness of such programmes and changes they would suggest for further support.

- Cancer Fund for Children should provide an internal training opportunity to present the model outlined in this report, and key findings from this report.

## External Recommendations

- Cancer Fund for Children will provide a targeted opportunity/s to share learning from this programme.

- Cancer Fund for Children to work with others across the sector and with the cancer registry to determine how future statistical mapping can include numbers of young people in Northern Ireland who are being bereaved each year through cancer. This knowledge will help to ensure there are robust systems and processes in place to provide support.

- Cancer Fund for Children to seek meaningful opportunities to present findings and learnings from this report to key decision makers, in an active lobby to seek resources for the continuation of this support and enhancement of it across all bereaved young people.

- Organisations working across cancer services should explore opportunities for joint learning in relation to bereavement support that is taking place and seek opportunities for partnership and learning.

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# Appendix 1

## Preparing the Way CBN UK (2018) Alison Penny

This report informed the development of an evaluation tool for bereaved children's services in the UK.

This report draws on the expertise and research of many dedicated professionals. These findings come from practice wisdom and the willingness of the families with whom they worked coming forward to participate in research studies. Those bereaved have taught the practitioners and researchers who have shared their insights for the benefit of other children, young people and their families. In particular, Dr Liz Rolls (2007) pioneering work in mapping and developing evaluations of post-bereavement support for children was the inspiration and foundation for this project and report. According to the Palliative Care Priority Setting Partnership (2015) the best way to support children and young people when someone close to them is dying or has died includes:

- Communicating with them about the diagnosis and dying process
- Enabling them to talk about their experience
- Providing bereavement support

The death of a close family member is associated with a range of poor outcomes for children and young people both in the short and medium term and into adulthood, including early mortality, mental and physical health problems and disrupted education (Penny and Stubbs (2015). For children bereaved of a parent through cancer, the time before the death is considered particularly stressful (Siegel et al 1992).

Over the past three decades a range of services have developed across the UK and Ireland to respond to the needs of bereaved children. (Rolls and Payne 2003, 2004;Penny 2011 and ICBN 2023). An increasing number of services are also offering support to children before a death, where this is possible.

## Evaluating Support

**The practice context:**
Whether individuals engage with services for children before or after bereavement, as funders, managers or actual or potential service users they have an interest in understanding whether it works. The report found that post bereavement services were struggling with the demand for evaluation information from various sources.

The most common form of evaluation was post-intervention user satisfaction surveys with self-completion forms. Data was patchy and evaluations of processes and outcomes were less common (Rolls and Penny 2011).

In 2007, Rolls recommended that the sector work together to develop a common core routine evaluation package that could be used across all services, comprising a basic dataset, user satisfaction survey and focused clinical outcome measure. This collaboration was taken forward by the CBN and the package is now in use in 25-30 services. Throughout the project, CBN members requested that the package might be adapted for use in services supporting children before a death.

**The research context:**
This request was supported by recommendations from research into interventions of support with children facing serious illness in the family which found that “while qualitative evaluations were generally positive. The quantitative evidence was limited in scope, mixed in quality and inconsistent in results.”CITATION . Researchers recommended consensus work to identify relevant outcomes and choose measures which would be sensitive to changes in these.

**The policy context:**
Policy responsibility for children’s needs when a parent, sibling or other significant person in their lives is dying lies across end-of-life care and children’s emotional and mental health. In both these fields there is an increasing drive for the routine use of patient-reported outcome measures. (PROMS).

## Aims of the Study

Were to:
- Review areas of concern to families and practitioners about children’s needs before a death in the family and attitudes towards accepting professional support
- Scoping interventions and building consensus on the aims of support services in the UK
- Reviewing current quantitative measures being used in evaluations in research and practice
- Identifying the key challenges to evaluating these interventions
- Proposing a draft suite of self and parent-reported measures to capture the changes towards outcomes across services working with bereaved children.

**Children’s experiences and needs when someone in the family is seriously ill**

The challenges children face when someone in the family is seriously ill include
- changes in family routines
- uncertainty and fear
- caregiving responsibilities
- lack of parental availability and attention
- separation anxiety
- loneliness and loss
- economic pressures on the family

(Spath et al 2007, Knecht et al 2015, Zegaczewski er al 2015, Walczak er al 2018, Eaton Russell er al 2018).

Both the literature on parental and sibling illness notes disruptions to functioning, levels of distress, physical symptoms, quality of life and self-esteem. And debates the longstanding negative consequences (Prchal and Landolt 2010. Berggren et al 2016).

The more positive outcomes like personal development, compassion and closer family relationships have received far less research. (Joseph et al 2009. Parchal and Landolt 2010. Aldefer et al 2010).

**We know that what helps children is:**
- Age-appropriate information about diagnosis and prognosis
- Support in communicating their needs with family
- Peer support from others who 'know' to reduce isolation
- Time out from the illness situation
- Support from friends
- Practical help
- A safe space to share how they feel and share their concerns
- Continuation of routines
- Tailored support for their individual needs

For parents, meeting these needs while dealing with an illness themselves or caring for someone else creates huge challenges.

Communicating about the illness and prognosis with children is a daunting task for any family. They need help and support from healthcare professionals on how to talk to, inform and support one another (Fearnley and Boland 2017, Kennedy and Lloyd -Williams 2009) as do children when a sibling is seriously ill (Patterson et al 2011, Lovgren et al 2016).

Many families face barriers in accessing support outside the family circle. The pressure of medical appointments and medical caring, getting to services and managing the everchanging trajectory of the illness can make it hard to find the time to acknowledge the situation and accept that children may need support. These process issues highlight ways of evaluating the outcome of interventions, indicating some of the areas needing to be considered.

## The Aims of Interventions:

In the scoping review there were diverse aims. These were grouped into seven main areas as follows:

- **Knowledge and attitude towards illness** (36% aimed to increase the child's understanding of the illness)
- **Coping** (32% aimed to improve the child's coping)
- **Psychological functioning** (32% aimed to reduce or prevent emotional, behavioural or social problems)
- **Parenting, family functioning and relationships** (30% aimed to strengthen parenting or family functioning)

- **Communication, expression and social support** (26% aimed to improve family communication, 11% aimed to increase the child's connection to others in the same situation).
- **Quality of life and functioning** (15% aimed to increase the child's wellbeing, and adjust the quality of life)
- **Self-concept** (11% aimed to increase the child's self-esteem)

## Issues with Assessment and Evaluation

As was expected, the great variety of outcome measures across services was one of the chief methodological weaknesses.

**Other weaknesses included:**

- Small sample sizes
- Short follow up
- Diversity of types of interventions
- Lack of process outcomes
- Lack of specificity of setting
- Lack of diversity among participants making it difficult to generalise results
- Underuse of control groups
- Under-reporting of response and attrition rates
- Lack of cost information

**Practitioners' concerns included:**

- Time constraints
- Anxiety about reducing families to "tick boxes"
- Wanting child friendly formats
- Trade-off between a comprehensive assessment measure and a sensitive outcome measure
- Illness progression causes unpredictability and requires flexible, tailored support which can be harder to evaluate

## Serious Illness in the Family Service Questionnaires (SIFSQs)

Focus group participants in the study, worked together on a series of draft questionnaires that capture changes towards the outcomes identified, and sought to overcome the identified evaluation outcomes. They recommended the following:

**Recommendations:**

- Services should select outcome measures that are appropriate to their context and aims.
- Services should introduce their baseline/ assessment measures as early as possible without disrupting the relationship practitioners are building.
- Services should consider when to do their post-intervention measurement to avoid coinciding with the death.
- Services should collect qualitative as well as quantitative data.
- Evaluation studies of pre-bereavement support for children should include process evaluations and careful reporting of refusal and attrition rates and reasons.

- CBN should approach collaborators working on palliative care outcomes and children's mental health outcomes to introduce the SIFSQs.
- CBN should work with funders to help them understand the challenges and possibilities of evaluating this type of support.

Penny 2018

# Appendix 2

## Review of the Bereavement Services within Cancer Fund for Children (2020)

### Vision and Purpose

Based on the 2020 review of the bereavement support offered to families by the Cancer Fund for Children a vision for the future of such support was developed to include:

- Our core values
- Minimum standards
- A programme of services (available for a three-year period post bereavement)

### Our Core Values

**Responsive:** to the needs and wishes of families. Recognising that the individual experience of grief is unique and seeking to offer tailored support that is flexible and available when the need for support arises within the three years post bereavement.

**Partnership:** working with families. The heart of the work is the ability to establish relationships with individuals and families at the most difficult time in their lives. Led by the wishes of the family we support and seek to ensure that their views are heard and respected.

**Professional integrity:** Our service is based on respect, reliability, honesty and non-judgement. We maintain professional boundaries and are knowledgeable and experienced in supporting families coping with bereavement. We seek to continually update and develop our skills and learning through training and development.

**Equitability:** We offer a consistent, appropriately resourced service to all families who are bereaved by cancer. We understand that individuals have the freedom of choice as to when or if they avail of bereavement support. A consistent offering of core services will be available to all families whom we support.

**Compassion:** We support individuals and families with warmth and sensitivity seeking to 'hold space' and listen without judgement. We support with dignity and respect.

## Minimum Standards

In respect of the varying needs of the families met by the service, minimum standards were developed to ensure:

- Equitability: all bereaved families are offered a minimum level of support, including those who did not have the opportunity to avail of services pre-bereavement due to the trajectory of the illness

- Being pro-active in offering all families support rather than the families needing to seek it out

- Opportunities for families to be reminded of information /services at different points of time following the bereavement

- A relationship is maintained, contact is made, and support is offered throughout the three-year period post bereavement as there may be greater need for this support in year 2 or 3 than in the early stages of their loss.

## Programme of Services

Currently bereavement support is offered to families for a three-year period.

**In Year One:**
These include:

- Individual support for children and young people aged 5 - 24 years
- Short breaks for bereaved families
- Dedicated Cancer Support Specialist
- Daisy Box
- Groupwork
- Parental support
- Closure Box
- Health and Wellbeing Mini Breaks for bereaved parents (three per year)
- Groupwork programme for children and young people aged 8-17 years

**Rationale:**

- Pro-active offers of support are important in Year 1. Some families will need support, information, signposting etc. in Year 1, while others will benefit from knowing that such support is available if needed at a later stage.
- Maintaining and developing pre-bereavement relationships during this first year is important at the time and as a foundation for accessing support at a later stage.
- Most families shared that the support they needed in the first year was from family, and external support was not needed in this period.
- Having a bereaved groupwork programme running each year for both the 8-11 and 12-17 age groups ensures that children and young people can access peer support at the time that is appropriate for their individual needs from Cancer Fund for Children.

**In Year Two:**
These include:

- Individual support for children and young people aged 5-24 years
- Bereaved short breaks for whole family at Daisy Lodge
- Health and Wellbeing Mini Breaks for bereaved parents (three run per year)
- Groupwork programme for children and young people aged 8-17 years
- Parental support programme
- Allocated Cancer support specialist

**Rationale:**

- A greater need for a higher level of support was identified in Year two.

> *"I found the 2-year anniversary extremely hard, I think I was just on auto-pilot for the first year"*
>
> *"Grieving process feels like it only started this year….. The 1st year a complete blur"*

- The bereaved members reflected that they needed different things in the second year of their grieving which often meant accessing external supports.

An offer of a visit early in Year two post bereavement has been proposed for both adults and children/young people in the family to coincide with the potential increased need for support. It is envisaged that this is likely to make the uptake of direct therapeutic support easier if required.

**In Year Three:**
Services include:

- Individual support for children and young people aged 5-24 years
- Bereaved short breaks for the whole family at Daisy Lodge. This includes a therapeutic session focused on the future and moving forward whilst carrying their I loved one with them
- Health and Wellbeing Mini Break for bereaved parents
- Groupwork programme for children and young people aged 8-17 years
- Parental support programme
- Allocated Cancer Support specialist
- Closure pack

**Rationale:**
- The focus of support in the third year is on preparing the family for closure of the service support in a planned supportive way, acknowledging that grief will extend across a lifetime and tailoring the supports to be reflective of this fact.
- A closure pack would be offered to each family at the end of the support which would include signposting information, tools with a self-support/care focus, resources and a personalised gift from the charity which names the person who has died.

- This provides specific support on a family basis around exploring the future and how to 'grow around grief'.

*"Workshops showing how to function through life while carrying your child with you"*

*"Family time focusing on the future!"*

## Assumptions

**Activity**
Cancer Fund for Children has offered a number of bespoke bereaved groupwork programmes in the past. These were developed in response to the needs identified by Cancer Support Specialists when working with families after the death of a sibling or parent. These have been delivered in the community and at Narnia.

A review of a bereaved sibling groupwork programme in 2017 evidenced that the young people who participated found that the programme allowed them to:

- Meet others who shared a similar experience
- Provide a space for them to remember the person who died
- An additional resource for parents in helping their child navigate grief

A survey completed by parents post-programme noted:

*"…. Good for the children to see other children who are going through the same things, and it gave them the opportunity to share their journey with others."*

*"Not on this journey alone. We hope that there will be more programmes like this in the future."*

*"The support evenings helped a lot – the children talk more about their brother J, and they enjoyed meeting other children in the same boat."*

*"As a parent we aren't sure how to help our kids through the grieving. This experience has been a priceless experience for them and us."*

Having a space to discuss bereavement, explore feelings and share experiences was noted as follows:

*"at the start, (I) didn't want to know what has happened to mum, (but) because every-one else talked about theirs and shared stories. (The) shared experience with others helped me to be and feel normal, Feeling a lot less worried now, talking more about my mum and talking to others and feeling better."*
Young person

*"I'm glad the group brought out (his) emotions…. It's what he needed as he'd been holding them in since his dad died."*
Parent

## Aims of Groupwork

Bringing grieving children and young people together who have lost a sibling or parent to cancer provides opportunity for them to:

- Meet others who have had a similar experience
- Reduces isolation
- Holding space for children and young people
- Provides opportunity to share stories and talk about grief
- This can be done in a safe, supported and facilitated environment
- Provides psychoeducation related to the grief process
- It can be preventive work alleviating the emotional wounds which can be carried by children for years and into adult life if their grief remains unacknowledged and unsupported

As Robert Neimeyer (2009) states:

*"Strategies …. That foster meaning making …. help…. re-establish a coherent self-narrative that integrates the loss, while also permitting their life story to move forward along new lines."*

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