

# Candlelighters

Supporting the families of children with cancer

**Impact  
Report  
2022**





# Some highlights

101

newly-diagnosed families started receiving Candlelighters support, in addition to the families we were already supporting

808

Our support is for the whole family, including grandparents, so this could be up to 808 new people supported based on an average of four in a family\* and two sets of grandparents

1,312

attendances by children and adults at 62 peer support groups, events and trips across 2022

341

families given financial support – grants and holidays

949

talking therapy and wellbeing sessions supported children and adults



# Welcome

to the Candlelighters 2022 Impact Report



Being told your child has cancer is the most devastating news a parent can receive. Instantly, their lives, and those of their whole family, are torn apart and will never be the same again. Their lives and hopes for the future are shattered and they face a long challenging journey that will affect the whole family – emotionally, physically, and financially.

Since Candlelighters was founded in 1976, we have been there for these families, providing the emotional, practical, and financial support they need at such an incredibly difficult time. We see the impact of a childhood cancer diagnosis first-hand every day, and it is our mission to bring light to these families through our support services, and to bring hope by investing in vital research to improve the outcomes and lives of children with cancer.

We are there for every step of a childhood cancer journey – from the moment of diagnosis until well beyond. Support from Candlelighters lasts a lifetime.

Because of your incredible kindness, support, and generosity, we have brought light to so many families facing an unimaginably difficult situation.

Together, we really can make a difference for families when they need it most. Please read about the impact you have made with immense pride for the difference you have made.

**Emily Wragg**  
Candlelighters CEO

*“When Maddie was diagnosed we felt that our world just stopped still. We were scared, shocked and just numb. Candlelighters have supported us as a family from day one, during the toughest time of our lives. Maddie rang her end of treatment bell in August 2020, Candlelighters continue to support us and we as a family will be forever grateful.” – Rachel, mum to Maddie*

# How your impact

## helped ease the financial burden of a childhood cancer diagnosis

Before the cost-of-living crisis hit, families of children with cancer already spent, on average, an extra £600 per month on increased costs associated with diagnosis. More recent research estimates this is now closer to £730\*.

These costs might include travel to hospital, accommodation, parking, and higher heating bills because keeping poorly children warm at home is essential.

This is in addition to the fact that many parents must take extended unpaid leave or give up work completely to navigate frequent hospital appointments and stays. With treatment often lasting up to three years, this sustained pressure on finances can lead to increasing debt and further stress and anxiety for families.

Thanks to your kind donations and fundraising, we can provide financial support for these families. This includes New Patient Grants, Emergency Grants, and Christmas Grants to help ease some of these pressures, as well as funding things like holidays to ensure families can make lasting precious memories.

Daniel's Family



*"The financial grants we received from Candlelighters were an absolute lifeline, as I was on maternity leave and my husband had to stop working to look after our other children at home, so we had no income. I stayed with Daniel at the hospital but travelled 70 miles home and back each day to see our two-month-old, which cost over £120 per week in fuel."*  
– Emma, mum to Danie

A childhood cancer diagnosis costs families an extra

**£730**  
a month\*

**174**  
Holiday Grants totalling  
**£25,800**

**2** Proton Treatment Grants totalling  
**£1,000**

**127**  
New Patient Grants totalling  
**£90,600**

**16** Compassionate Grants totalling  
**£4,800**

**229**  
Christmas Grants totalling  
**£22,900**

**16** Financial Assistance Grants totalling  
**£4,055**

**£149,155**

In 2022, 564 grants totalling £149,155 were given to families, to support them with the additional costs that a cancer diagnosis brings



# How your impact helped children understand and cope with their feelings

Going through childhood cancer is a stressful, upsetting, and confusing journey. For a child (whether a patient or sibling), a cancer diagnosis can be very scary and unsettling, and the emotions they experience can have a huge impact on their wellbeing. We provide a range of support especially for children to help them on their journey through childhood cancer.



*"It's only in recent months we have started to see the effect Evie's journey has had on her mental health. She's doing very well in articulating her feelings and anxieties but that's not without tantrums and meltdowns. Of late, memories of her time in the intensive care unit were triggered by a smell she associated with her time up there. The support we receive from Candlelighters is amazing and we are so grateful."*  
– Katy, mum to Evie

## Talking Therapy

Candlelighters provide talking therapists specifically trained to work with children, to help them understand and cope with their situation.

Helen Crossland, one of our talking therapists, explains:

"When I work with a child – a patient or their sibling – the sessions are centred around encouraging them to identify their feelings and worries, such as grief, fear or anxiety. It might be that they need support with behavioural issues, too.

"I will often do some play therapy with the child – for example, working on cards or exercises – to explain some of the emotions they may be feeling, such as anger or grief. I also work with the child's parent or guardian to discuss the tools that have been provided, so they can be introduced and continued at home and outside of the talking therapy space."

222

talking therapy sessions  
for 86 children







188

attendances at 16 children's groups & trips

## Peer Support Groups & Trips



It is vital for children to be able to connect with others in a safe environment, to be able to share their feelings, and just feel normal again.

Candlelighters provides peer support groups for patients (both on treatment and post-treatment), siblings, and bereaved siblings. The groups have lots of fun activities and in 2022 featured many activities, from crafts and games to pizza making and handling animals.

*"I am 10 and my brother Jack is 13 and we have been attending Candlelighters sibling and patient group activities for the past four years. It's been a nice experience because of the fun activities with other kids, it makes me feel accepted. The staff are helpful, kind and always smiling. It has boosted my courage with school, and it has raised my self-esteem because I was very glum about life and my brain tumour. Thank you for supporting Candlelighters and giving us these experiences."*

– Rowan, patient supported by Candlelighters

41

41 attendances at 4 groups for bereaved siblings



24

4 attendances at 3 groups for siblings



40

40 attendances at 3 groups for patients



25

25 attendances at 1 residential trip for siblings



25

25 attendances at 1 trip for siblings



33

Young Dreamers – children's activity and feedback sessions



33 attendances at 4 sessions for children

# How your impact supported parents with their mental health and wellbeing

For parents and carers, a child being diagnosed with cancer is unimaginably upsetting and confusing. As well as facing overwhelming emotions, a parent may need to stay on the ward with their child during treatment for months on end, potentially taking them away from their other children, partner, and job. We ensure family members are not alone by supporting them during every step of this indescribably difficult journey.

Our talking therapists support parents and carers in finding solutions and coping strategies – easing their worries and helping relieve pressure. They specialise in coping with bereavement, anxiety, depression, panic attacks, sleep management, post-traumatic stress disorder (PTSD), and breathing exercises. This in-depth support takes place in a safe space and is tailored to the parent's needs. They may want support with juggling everything while their child is in hospital, with coping with particular issues, or just to let off steam in a safe environment, with no judgement.

Helen &  
Rosie



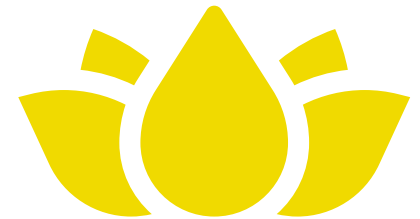
38



hairdressing appointments  
for family members staying  
on the wards

224

talking therapy sessions for  
family members



503

wellbeing appointments  
for family members

*“After every talking therapy session, I would feel like a weight had lifted from my shoulders, and I can’t articulate the difference this made to my mental health. It ensured I was resilient and strong enough to support and care for Rosie.”*

– Helen, mum to Rosie





←  
Jen &  
Eden

Spending long periods on the wards and going through such a stressful time, can leave parents emotionally and physically exhausted. To support their child, it is vital they are provided with care themselves. We offer free massage, reflexology, and hair appointments to family members, which can make an enormous difference to their wellbeing, but can be impossible for them to find time for. Families tell us that having this space makes them feel revitalised and better equipped to support their child and the rest of their family.

*"My routines and 'normal life' are totally different now and to be offered a free haircut was more welcome than I ever thought possible. Candlelighters made me see that if I look after myself then I am better placed to look after Eden. Sleeping on the fold-up beds and excessive stress in my shoulders takes its toll so I also gladly take up any offers of massage whenever I can – guilt-free."*  
– Jen, mum to Ede

Parents and grandparents also benefit from our peer support groups. These are held at the Candlelighters Family Support Centre and locations across Yorkshire. From afternoon tea for mums to foot golf for dads, the groups give parents and grandparents the chance to meet others in similar situations, to share stories and experiences, and have some normality.

*"Not only did the Candlelighters Bereaved Mums Group put me in touch with other mums in my situation, I have made some lifelong friends through this group – not only with the mums but the Candlelighters team too. I can just be me; they 'get it'. When I am there, I am no longer the lady whose child died, I am me."*  
– Stace, bereaved mum to Jake

# 162

attendances by parents and grandparents  
at 17 peer support groups

## 18

18 attendances  
at 3 groups for  
bereaved dads



## 45

45 attendances  
at 4 groups for  
bereaved mums



## 26

26 attendances  
at 4 groups for  
grandparents



## 12

12 attendances  
at 2 groups for  
dads



## 30

30 attendances  
at 3 groups for  
mums



## 31

31 attendances  
at 1 group for  
parents



We also held

## 12

Family Community Days  
77 attendances at 12  
walk & talk picnics



# Maisie's story

## told by dad, Rob

**We're the Kane family from Pocklington, York - me Rob (dad), Chantel (mum) and our two daughters – Abigail, aged four, and Maisie, who is 19 months old. Maisie was diagnosed with leukaemia in March 2022, at six months old.**

Maisie's diagnosis was a massive shock. We felt numb and had so many emotions to deal with, which was tough as we had a lot to understand about Maisie's treatment and needed to be there for her. Maisie began intense chemotherapy at the Leeds General Infirmary (LGI), and had to stay on the hospital ward for two months. She responded well to the treatment; however, it left her really fatigued, and she suffered from several side effects.

It was on the ward that we first met Candlelighters, when the Family Support Team introduced themselves and gave us a welcome pack. They also offered us a room at The Candlelighters Cottage, which was an absolute godsend. Only one of us could stay with Maisie on the ward, so having the room at The Cottage meant the other could be nearby. During this time, Abigail stayed with her grandparents in York for the start of the week so she could go to nursery, while Chantel stayed with Maisie on the ward and I stayed at The Cottage. I then brought Abigail to Leeds midweek, so she could spend time with her mum at The Cottage while I was on the ward. It was tough, but having The Candlelighters Cottage made such a huge difference. Travel costs mounted up, but the financial grant we received from Candlelighters was a huge help.

We were also both lucky enough to receive sick scheme pay from our employers.

The Candlelighters support on the ward was great. There was always someone to help if you were having a hard day – offering a cup of tea, having a chat, or sitting with Maisie if we needed a shower etc. We were also offered haircuts and massages at The Square, which were a welcome change and made us feel half normal. The Square is a really nice space for time away from the ward, and there was always a friendly face and someone to chat to.

Maisie then received two month-long cycles of immunotherapy at home, before being readmitted to the LGI for a three-month course of more intense chemotherapy. During this period, we were able to stay all together in the Candlelighters Cottage – including Maisie. She would have treatment

during the day, and we would then stay at The Cottage in the evening. If there were any concerns, the hospital was a minute away. It would have been so much harder if Maisie had had to stay on the ward or we'd had to travel from York every day.

Following this treatment, Maisie began maintenance at home. We visit the LGI every six weeks for a review, and there is always something going on that Candlelighters have organised – from performers in the clinic to Santa at Christmas. This makes the hospital environment seem less clinical and, despite everything, Maisie doesn't mind visiting. It's hard to drag Abi away sometimes too!

Maisie is doing well and, fingers crossed, she will finish treatment as planned in March 2024.

The support we receive from Candlelighters continues outside the hospital environment, and we know they will be there for us throughout our journey. We went to the Candlelighters Christmas Party last year, and we've attended some of the wonderful family days they organise. Candlelighters really have made such a difference to us.





# How your impact helped families stay together during a child's cancer treatment

**Children from across the breadth of Yorkshire receive their cancer treatment at Leeds. This means as well as the exhausting impacts of treatment, children and families are faced with the prospect of lengthy travel arrangements, being separated from friends and family, and missing much-needed home comforts. Often, one parent is either away from the child with cancer or away from their sibling(s) for extended periods of time.**

The Candlelighters Cottage is a home-from-home accommodation, giving families from further afield somewhere to stay. Just a short walk away from the children's ward, The Candlelighters Cottage allows families to stay together at a time when they need each other more than ever.

The Clegg family from Hull stayed at The Candlelighters Cottage when their son Brandon, who had just turned 17, was diagnosed with leukaemia in June 2022. Brandon's mum, Lisa, tells their story.

"When Brandon was diagnosed with leukaemia and transferred immediately to the Leeds General Infirmary, we felt like our world had fallen apart. Restrictions at the hospital meant only one of us could stay with him, so we agreed this would be my husband as he doesn't drive. I travelled back and forth to Leeds from our home in Hull each evening to see them, which meant I could keep working during the day to pay for the extra fuel we needed.

"Brandon felt ok with his early treatment, but became very ill when his intense rounds of chemotherapy started. At this point, he needed us both during the day. I stopped working so I could be with him at the hospital from early morning until late at night.

"We were given a room at The Candlelighters Cottage for as long as we needed. It was a massive lifeline for us. It meant we could be there together in Leeds to support Brandon 24/7 and I didn't have to make that long journey each day. Brandon ended up being in hospital for six months and the Candlelighters team were there

for us all every step of the way. If it hadn't been for Candlelighters, our journey would have been a lot harder than it already was."

Sometimes there can be more families in need of accommodation than The Cottage can house. We are determined to ensure that all families always have somewhere to stay should they need it, which is why we also provide funding to Eckersley House – a home-from-home accommodation owned and run by The Sick Children's Trust opposite the hospital's Clarendon Wing. If needed, we also book families into local hotels or apartments.



**35 families spent a combined total of 912 nights at The Candlelighters Cottage**

**£10k**

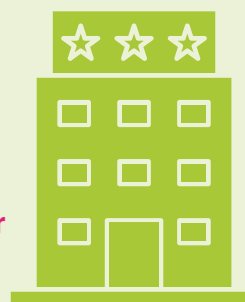
**We provided £10,000 in funding to Eckersley House in 2022. This provided 77 nights' accommodation for an additional 11 families**



**We also booked**

**47**

**hotel rooms near the hospital for families**





# How your impact helped children and families escape cancer, just for a while

When a child is diagnosed with cancer, it becomes more important than ever to spend time together as a family, make memories, and have some fun and escapism from the day-to-day reality of cancer. Candlelighters host numerous events for the entire family, across Yorkshire, designed to provide fun and relief. The events all take place in an environment where families feel safe, where they can be themselves and know that everything is in place for their child's needs.

Our family fun days and events gave families the opportunity to enjoy so many wonderful experiences, from bushcraft to riding in a fire engine and flying in a helicopter.

One magical event for children and their families is the annual Candlelighters Christmas Party, which returned in 2022. The party has costumes and characters, meet and greets with Santa, presents, food, music, games, and lots of happiness and fun – helping make Christmas truly magical for children with cancer.



*"It's hard to explain how much the Candlelighters Christmas Party meant to me and my whole family. Daniel was undergoing the last round of his cancer treatment but, thankfully, he was feeling well enough to go to the party. From the moment we arrived, we all had huge smiles on our faces! It was a day to make memories as a family, with the thought that it could have potentially been our last Christmas all together always at the back of our minds. The party brought so much joy and magic to us, at a time when we needed it most." – Emma, mum to Daniel*





Also incredibly important for families is the opportunity to spend time together as a family unit. When a family receives a childhood cancer diagnosis, priorities instantly change and daily life becomes unrecognisable. A family holiday might feel like an impossible idea, as finances are often incredibly stretched as many parents have to give up work, and treatment can involve lengthy hospital stays.

However, this is the time when these families need a holiday the most – to have a much-needed break from the day-to-day difficulties of cancer, and make precious, happy memories together.

Every year, Candlelighters offers families whose child has been diagnosed with cancer the chance to have a fully-funded break. Our family holidays allow families some much-needed quiet time away from the reality of the hospital wards, where they can escape cancer and just enjoy time as a family.

***“When my daughter, Harlow, was diagnosed with leukaemia at 18 months of age, our world was turned upside down.***

***The stress of constant hospital trips, medication, and seeing our child so sick was so difficult, not to mention exhausting. Harlow’s diagnosis also had a huge financial impact, as I had to give up work to care for her. When Candlelighters offered us a family holiday, it was amazing, and we were overwhelmed by their kindness. We took a break to Center Parcs, which was so special. It allowed us to reconnect as a family, have some time away from the hospital and just enjoy some fun together.”***

**– Esthe , mum to Harlow**



**£25,800**

of holiday grants given so families can enjoy extra treats on their holiday



**269**

7 family fun days for 269 children & adults



Halloween party attended by

**71**

family members

**146**

We paid for 146 family holidays in 2022



# Bringing light and support to families at the hospital

**When a child diagnosed with cancer is admitted to hospital, it can be a lonely and isolating time for them. Suddenly being away from their friends and siblings can be very tough, as they miss out on their normal routine and spending time with other children.**

Because of the generosity of supporters like you, we can make this difficult time a little easier for families. We work hard to make the wards and clinic feel less clinical and more enjoyable, bringing some comfort and fun to the hospital environment for children and their families.

The Candlelighters Family Support Workers are on the wards and at the clinic to bring some much-needed fun and distraction to children – playing games or doing activities. They also give tired parents incredibly important respite, and work alongside Candlelighters-funded play leaders who, as part of their role, use play to relieve anxiety by helping the child prepare for a procedure or understand their treatment.

*“The support on ward was invaluable, especially in the very early days of diagnosis where we were lost in a world of unfamiliar faces, vocabulary, feelings and emotions. The team were there to give us parents a break when we needed it and to play with Oliver when he needed a change of scenery.” – Laura, mum to Oliver*



In 2022, we were thrilled to be able to extend the time our Family Support Workers are at the hospital from 7.30am to 7.30pm, Monday to Saturday. This will help hugely with children’s wellbeing, helping them cope with day-to-day hospital life, deal with anxieties or simply relieve boredom.

In addition, we fund a number of roles at the hospital – from play leaders and the Candlelighters Dinner Supervisor, to speech therapists and paediatric radiographers – helping ensure that children receive the best possible care during their cancer treatment.

We also run events at the hospital for children and their families, bringing fun and escapism to the hospital environment. From magic shows to pizza parties, there’s something for everyone.

Candlelighters staff provided

6,322

hours of support at the hospital



We funded

12,282

NHS oncology staff hours



# Here are just some of items we bought for the hospital in 2022:

## Keeping children entertained:



a Toniebox



a Bluetooth speaker



two TVs for Ward L31



an Xbox for the Teenage Ward



toys and crafts for the hospital playroom and clinic area



a wooden play kitchen



a chocolate fountain



a TV and DVD player for the Pavilion



refreshments for the Pavilion



## Keeping family members and hospital staff comfortable:



refreshments for families and hospital staff at the clinic



five recliner chairs for the hospital



a coffee machine, furniture and a fridge at the clinic



furniture for the Pavilion



two coffee machines



a fridge freezer, microwave and air fryer for the Parents' Kitchen



*"I first experienced Candlelighters the day Eden was diagnosed, and we were transferred to Leeds Children's Hospital. That first night, I was in a very dark place mentally and just wanted to go home. Ladies in pink kept offering to make me a cuppa and asking if I needed anything. I couldn't eat for a few days but when I was ready, crisps and biscuits were available in the parents' room all thanks to Candlelighters. This might seem like something small but to me it was huge." – Jen, mum to Eden*

# Reducing hospital stays for children with cancer

Dr Bob Phillips



Can you imagine life for you and your family if you had a child who needed to stay in hospital for months on end? This is often the case for a child with cancer, who may need to spend significant periods of time in hospital – usually with one parent staying with them whilst the rest of their family is at home.

This creates a huge mental and financial burden for the family. Away from their usual support networks – family, friends, school, and colleagues – children and parents feel isolated and lonely. Parents often take large amounts of time off work or stop working altogether, exacerbating the increased costs a childhood cancer diagnosis has for a family. Hospital stays are often unexpected and frequent, causing disruption for children and their families, who want as much precious time at home as possible. But it doesn't always need to be this way.

Your support has enabled Candlelighters to invest in research with Dr Bob Phillips and Dr Jess Morgan to help reduce hospital stays for children.

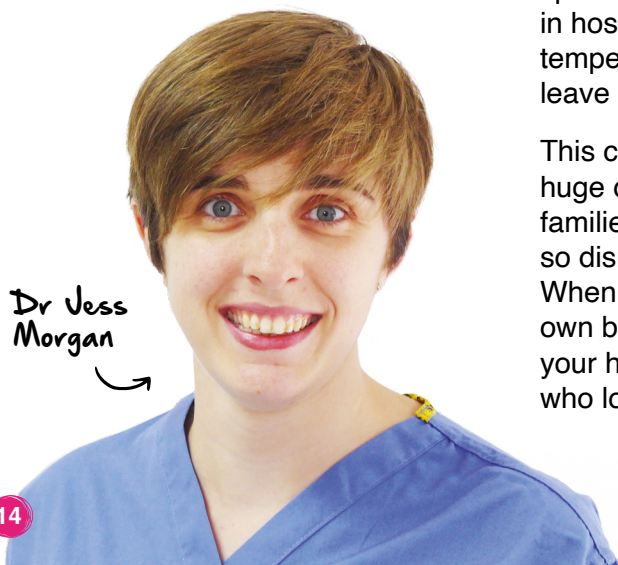
This research has focussed on a condition called febrile neutropenia – a fever that is

common for children with cancer. Because febrile neutropenia can sometimes be life-threatening, any child with this fever would be admitted to hospital for seven days for treatment with intravenous antibiotics. However, some children may just have a cold or other minor condition, meaning a long hospital admission and antibiotics are not necessary.

Drs Phillips and Morgan worked with researchers across 16 countries to successfully develop a safe method to identify which children with febrile neutropenia could safely return home early. This method is being rolled out across the UK and as far away as Australia. By the end of 2022, 30 centres across the UK were safely allowing children to return home early.

Now, a child with febrile neutropenia who is identified as safe to be sent home early will spend, on average, just two days in hospital as a result of their temperature – with some able to leave after as little as eight hours.

This crucial change will make a huge difference to children and families whose lives are already so disrupted by childhood cancer. When you're ill, you just want your own bed and to be surrounded by your home comforts and people who love you.



Dr Jess Morgan

# 1 in 2

children with febrile neutropenia could go home within 2 days instead of 7

*"The unpredictable nature of needing to visit hospital any time my son had a temperature or was unwell meant we needed to rely on our employers to be flexible and understanding. In one situation, my son spent four days in hospital, came home for about 10 hours, had to be readmitted for another day, came home again and then needed to be readmitted again the next day for another three days. Each time, my partner and I took turns to go in, usually late at night with one of us needing to explain to our younger child where the other kept disappearing to."*  
– Ste, dad to Aspen

Candlelighters have funded childhood cancer research for the last 40 years. In the last 20 years alone, we have invested £9m in vital research.

Our research is helping to improve the chances of survival and quality of life for children affected by cancer, across our region and beyond.

# £3000k

of research funded





# Your amazing support in 2022

Nothing we did in 2022 would have been possible without you – our amazing supporters. As always, we were blown away by your kindness and generosity in coming together to raise funds and show your support for the families of children with cancer. Every £1 raised helped them know they were not alone.



# £2,040,000

was raised by our amazing supporters, through fundraising or donations, which meant we were able to provide all of our support services to families who so vitally need them, as well as investing further in research.

# 190 3,316

In 2022, 190 people volunteered an amazing total of

hours of their time for Candlelighters!



All of the support we provide to children diagnosed with cancer and their families is free to them but is not free for us. We must raise every penny, and we are so thankful for your inspiring support in 2022, and your incredible impact on children and families facing childhood cancer.

# Candlelighters

Supporting the families of children with cancer

*"The impact of the diagnosis is hard to put into words. It's a bit like a grenade being thrown into your family life and everything is changed, whilst you try to continue as best you can. Candlelighters have provided us, as a family, with such an incredible amount of support. The Candlelighters staff on the clinic and wards are brilliant – they really do make a difference. My first encounter with them was on our very first day in clinic, when Nina began chemotherapy. I was feeling completely overwhelmed and scared, and someone from Candlelighters smiled, said hello, and offered me a brew. It's really those small acts of kindness and warmth that help you to navigate the world that you find yourself in."*




– Vikki, mum to Nina



For family support, please call **0113 887 8333**

To make a donation you can give online, call **0113 322 9283**, or send a cheque to the address below. You can also leave a gift to Candlelighters in your will.

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