

IMPACT

22/23

R E P R T

**CELEBRATING
40 YEARS OF CARE**





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Message from the Chief Executive

As Acting Chief Executive of Northern Ireland Hospice and Children's Hospice, it is with great pleasure that I welcome you to our 22/23 Annual Report. I am honoured to present a comprehensive overview of our organisation's achievements and milestones, as well as the challenges we have navigated over the past year.

Over the last year, our teams have worked tirelessly to deliver care to individuals and families in need of our vital services. The demand for palliative care services is ever-increasing and our teams have surpassed themselves in delivering exceptional quality care and in supporting patients and families to have the best quality of life, right through to the end of their lives. Our teams have also continued to provide essential support to bereaved families, helping them to adjust to life in the absence of their loved one and ensuring care continues for as long as that support may be needed.

I couldn't be more proud of the entire Northern Ireland Hospice team for consistently going above and beyond the call of duty in their support of our patients and their families.

Last year was a momentous year for our Children's services as we marked 21 years of Children's Hospice care at Horizon House. To commemorate this significant milestone, we brought Elmer's Big Belfast Trail, a family-friendly ten-week public art trail, to Belfast. The event saw over 70 eye-catching and colourful elephant sculptures displayed in iconic locations across Belfast City Centre, uniquely designed by local artists, schools, and community groups. The event generated huge footfall and economic benefits to Belfast, attracting a phenomenal 241,935 visitors, with a total event economic impact of £12.5m. We were also delighted to receive the Freedom of the Borough honor bestowed by the Antrim and Newtownabbey Borough Council.

Furthermore, we also co-hosted the All-Island Children's Palliative Care Conference to mark 21 years

of Children's Hospice care gathering like-minded individuals and experts around the world to explore and shape the future of children's hospice care. We are very appreciative of the generous support we have received from our local community over the past two decades who have helped to fund the continued delivery of our services and enabled us to be there for children and families when they need us most.

Looking ahead, I am hopeful for the future of Northern Ireland Hospice, despite the obvious challenges we face. As an organisation, we remain committed to enhancing our fundraising efforts, forging, and strengthening our community and corporate partnerships, and exploring innovative avenues to secure the necessary funds to sustain and develop our services. We also remain committed to investing in our staff and their well-being through greater communication, appropriate resources, and training.

None of our achievements would be possible without the continued support and generosity of our supporters, volunteers, corporate partners, board members, and our staff. Together, we have achieved remarkable milestones and positively impacted the lives of thousands of families in need. With your ongoing support, I am confident that we can overcome the financial and economic challenges ahead and continue to provide exceptional palliative care to those who need us.

Trevor McCartney

Trevor McCartney
Acting Chief Executive
Northern Ireland Hospice



Our Year in Numbers



Our Challenges

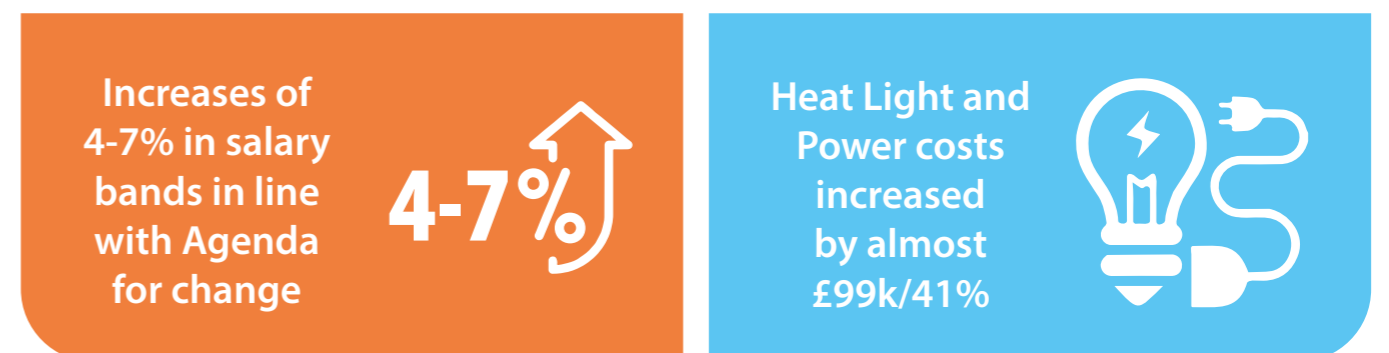
The historic structure of statutory income continues to be a challenge for NI Hospice, as with many hospices across the UK. Our funding from the Health Service through various bodies, is only 34% of costs, a level which is not sustainable and increases our dependence on the support of individuals and companies in order to deliver these vital services.



The wider Northern Ireland political context renders it increasingly difficult to influence the funding cuts that are being made in the Health Service, particularly in the absence of legislation giving a right to palliative care here, in contrast to the position in England. Fundraising in the current economic context of rising inflation and pressures on household expenditure is a challenge. Whilst, thanks to our amazing donors we have seen a 5.3% increase in donations against the previous year, there are increased costs in paper and postage, contributing to an overall increase in fundraising costs. We continue to review how we fundraise to ensure the best possible return on investment.



We work in a highly regulated environment which whilst ensuring that we can prove the excellent quality of care we provide, also carries a financial burden. Additionally, to attract the best quality staff we pay Agenda for Change rates in line with the wider health service in Northern Ireland and this means that cost of living uplifts are outside of our direct control. Combined with wider inflationary price pressures and the ending of favourable contracts, we have seen significant increases in areas such as heat, light and power (41%). We continue to work diligently to manage these costs.





We are Northern Ireland Hospice



We provide specialist palliative care to improve the lives of and provide comfort to babies, children, and adults with life-limiting and life-threatening illnesses throughout their lives. We support our patients to have the best quality of life, from diagnosis to the end of their lives, delivering holistic and specialist palliative care which is life-affirming and supports anyone who is affected by a palliative diagnosis including patients, families and health and social care professionals.

We do this through:

Our Hospices

We have two specialist Hospice units, Somerton House, our Adult In-Patient Unit and Horizon House, our Children's In-Patient Unit, which is the only Children's Hospice in Northern Ireland. Our multi-disciplinary teams provide high-quality patient-centred specialist palliative care as well as compassionate emotional and spiritual support, wrapping our approach to caring around the entire family.

Our Community Services

We have seven teams of Specialist Community Nurses that deliver care across

Northern Ireland. These nurses support children, adults, and their families by working closely with social workers, GPs, District Nurses and community pharmacies to identify each person's needs and develop personalised care plans which reflect individual choice.

Hospice at Home

Our Hospice at Home service provides practical one-to-one nursing care during the day, evening, or night to allow family members to have a break and look after their well-being.

Our Education Programmes

As the largest Hospice care provider in Northern Ireland, we deliver bespoke, high-quality education programmes and contribute to research as a member of the All-Ireland Institute of Hospice and Palliative Care and the Palliative Care Research Network Northern Ireland. This enables us to share our expertise for the betterment and furtherance of specialist palliative care for children and adults.



Our Vision

Is that infants, children and adults with life-limiting and life-threatening illnesses and their families, receive palliative care of the highest standards, thereby maximising their quality of life.

Our Mission

Is to inspire and deliver excellent and compassionate specialist palliative care via effective service models underpinned by exemplary education, innovation, and research.

Our Values

We believe in:

- A culture of respect and acceptance without distinction or judgement, where everyone can belong.
- Acting with courage, compassion, and integrity to add value to all that we do.
- Being pioneering, professional and accountable to deliver our very best.

Joanne's Hospice Story



Joanne's mum Beth and her close friend Tina talked about their experience with hospice care when Joanne came to stay at the In-Patient Unit, Somerton House.

Beth and Tina described 44-year-old Joanne as a bubbly, outgoing and a fun loving woman who would liven up any room that she went into. "She loved karaoke" laughed Tina, "her 'go-to' songs were Gina G, ooh ahh, just a little bit and Rose Garden. She didn't care if she could sing or not, she just gave it everything!" That was how Joanne approached life, she didn't want to miss a second and she put her children first. "She was a very loving, good mum and she always wanted to help people", remembers Beth. Joanne met her husband Graeme on a blind date and fell in love, Graeme and Joanne went on to have two children, Brodie and Faye.

When their first child Brodie was born, Joanne was first diagnosed with melanoma cancer. She fought bravely and beat the disease but tragically in 2009 her husband Graeme fell sick and died. Joanne kept going, focused on her children, family and friends and in 2015 she began a relationship with Gavin and was very happy. Tragedy struck again and in 2017 Gavin was killed in a road traffic accident. Two weeks after Gavin's death, the family suffered a further trauma when Elaine, Joanne's sister, also died. "They were more than sisters, they were really close friends", said Beth, "it was a devastating time for Joanne and us all."

After this terrible time, Joanne discovered a large lump in 2019. When it was investigated, she was told that, after 14 years of good health, the cancer had returned and it had spread throughout her body and into her brain. Beth remembers receiving the phone call from her daughter, "she just said, the cancer is back mum, you'll have to move in with me". Tina was at work when she got

a text from Joanne asking if she was free, "I just had a feeling that something wasn't right. I called immediately and she just told me that it was back and asked me to tell our friends. I was completely unprepared for that news - I just felt shattered."

Beth moved in with Joanne to help her because the consultant had told her that Joanne only had weeks to live. There were many days Joanne was too exhausted to leave her chair but she retained her passion for life and planned a 'cancer party'. Her event raised £7,500 for a cancer charity. She talked to her mum about her funeral plans and planned everything down to the smallest detail – including her eulogy and her sparkly red coffin!

One morning Beth wasn't able to get Joanne to wake up, so they called an ambulance to take her to hospital. When the consultant examined Joanne, he immediately referred her for specialist palliative care at NI Hospice.

Beth spoke about coming to Hospice, "We raced here in an ambulance and when she was admitted into Hospice, the sense of relief was unbelievable. I felt like a weight had been lifted off me and I knew I didn't have to do this without help. I really can't explain how that felt to me. When you know your daughter is going to die, to have people that will share the care burden is priceless, it's the one memory that stays with me - the overwhelming feeling of relief."

Even her room in Hospice was great, with her own bathroom, it meant that I could stay with Joanne and get washed without having to go home. The room had its own entrance which led out to the garden, it was lovely to have that space. The team

at Hospice even gave us our own room so we could stay over, they got us coffee and food in the evening. It sounds like just little things but when you are waiting and sitting in the room, those things mean the world to a family. "

Tina remembers the different levels of care and attention that they received at Hospice, "In my work I would have been coming to Hospice as a salesperson – I never thought I would be coming into the building as a visitor. But coming into the Old Schoolhouse Café for a break from the waiting was amazing, you were immediately given space, comfort and understanding by the staff and volunteers – it was a real haven for me."

"The care Joanne received was just amazing," Beth commented, "I was a care assistant and I would be very critical of the standards of care but I couldn't fault the quality of care that Joanne received. The Healthcare Assistants came and changed Joanne, making her comfortable and looking nice and pretty. Because Joanne wasn't conscious, their efforts made all the difference to me – she looked comfortable and like herself which made the situation a little easier for us."

"Joanne was admitted on Monday and on the Saturday the doctor said to me, don't go too far today. I was just in the room and my husband decided to go out into the garden, the sun was shining and the garden was beautiful, it was a very peaceful moment. With the rays of the sun coming into the room, I was able to spend a quiet moment with Joanne and say my goodbyes.

I will never forget that moment.

The Hospice team worked together to make life comfortable for my daughter and it allowed me to be with her. If Joanne had remained at home, I would have been washing her, turning her and changing the bedclothes, I would have had some help but that's what my last days with Joanne would have been focused on – instead of having the time when she wasn't in pain, was comfortable and I could simply just be with her."

Joanne passed away on Saturday 12th October 2019.

Rest in Peace.



Northern Ireland Hospice

LITTLE moments BIG memories



Meet our

Little Star Eilidora

Four-year-old Eilidora – also known as Nora – lives with a rare genetic condition and has been cared for by Hospice since she was two. Her mum, Grace, tells us the story of Nora.

Nora is very bold – she loves her brother and sister but loves to hear them getting told off! She loves it when people talk and sing to her, music, and stories. She loves lights, getting out for walks and going in the hot tub and the bath.

Nora developed normally for her first three or four months and then started to have seizures which they initially thought were infantile spasms. Then we got the diagnosis she had SCN8A, a rare genetic condition that can cause a whole spectrum of things that she suffers with – seizures, developmental delays, feeding issues, respiratory issues – all sorts of issues.

She is non-verbal but definitely tells you when she doesn't like something! We also get squeaks and smiles, a lot more smiles this year. Fingers crossed they last. She's always got a little smile for her daddy!

When Nora was about two, we had some serious feeding issues and were in hospital for a long time. That was when Hospice got involved. We met Rosie, the palliative care nurse linked with the Royal Hospital. A hospital nurse told me, *"The palliative care team are coming to meet you"*. Immediately I was thinking, *"They know something I don't. This is really bad. Why are we meeting the palliative care team?"*



I was scared and really resisted it. I probably wasn't the nicest to Rosie! But they were really patient with us, persistent and respectful as they talked us through it. We realised that it's not just about caring for Nora at the end of her life, it has been much more than that. I'm so glad I stopped resisting!



We've been able to stay more recently at Hospice. For us, there's nothing better than being able to go and put your head on the pillow and get a full night's sleep, knowing that Nora's safe with people you can trust.

Nora loves it! She's pampered like a princess when she's there. They do massage, painting and music therapy. We arrived back one day, and she was on the water bed in the sensory room with someone playing guitar and singing to her. A lovely way to spend an afternoon!

When we go there, they set up the den and we can all sit together stress-free as a family and watch a movie. And if Nora needs suctioned or has a seizure halfway through, they can take care of that.

There are little things that people take for granted that are so important. It doesn't happen very often, but Hospice's support makes those things possible for me and my husband, Gerard. It is just really, really important to us and makes life more bearable. Whenever you live a life like this, it's hard. But when there's people that help you and care about you and genuinely will do anything they can to help you, there's nothing like it.

Hospice has done a lot for us. Our community care hospice nurse, Bethany McCracken, became our guardian angel. She couldn't have done any more for us. We've had Hospice at Home where Hospice nurses have come here and sat with Nora, which was great – especially when Eilidora's younger brother Fionn was a little baby – so I could nap or do the dishes.

We missed the assisted short breaks in the Children's Hospice during COVID. We all visited before the pandemic kicked in – Fionn was a month old at that point – so it was full on, but great. Edie has done the Hospice's summer schemes. It's good for her just being around other siblings that have sisters or brothers like Nora.

Little Stars





Our People

Northern Ireland Hospice recognise that its people play a key role in its success.

As we recover from the impact of the COVID-19 pandemic, the continued development and well-being of our staff have remained our main priorities.

We will continue to:

- Attract and retain key talent - we have successfully recruited our first IT higher-level apprentice and nurse through sponsorship.
- Introduce channels for two-way engagement and feedback across the NI Hospice for management and staff of all levels.
- Implement wellbeing initiatives through our Wellbeing Strategy.
- Recognise our people and reward their performance and dedicated service.
- Develop our people professionally and personally in a supportive, diverse, and inclusive environment where we can empower them to be their best.
- Strive to be an employer of choice.

We have introduced our Well-being Strategy where the focus has been on 4 key areas:

- Mental health
- Physical health
- Financial wellbeing
- Social wellbeing

A series of Wellbeing Cafes were hosted to give staff the opportunity to give their feedback on their wellbeing and tell us what was important to them. This feedback has formed our three-year well-being action plan. A number of initiatives across all four pillars have already been introduced in which staff engaged, and feedback has been positive.

Following on from last year's Best Companies survey, where we received a "one to watch" rating, we have listened to the feedback from our teams, and this has enabled us to empower our staff to share their feedback. We have been able to implement initiatives to promote engagement, two-way communication, and inclusion, to give our people a "voice" in the organisation and to nurture the feelings of being valued.

We want our people to perform to their best and in support of this we have adopted a more flexible approach, where possible, to enable the balance between work life and home life whilst meeting service needs.



Our Volunteers

Underpinning all our work and our ability to provide specialist palliative care to local patients and their families, are our volunteers. We are incredibly grateful to have the support of over **700** committed and passionate volunteers working across the organisation, providing over **126,000** hours of their time to enhance the quality of care and support that Northern Ireland Hospice provides to those who need it. This amounts to over **£1.2m** of hours at the current minimum wage and carries even greater value for the organisation.

Our volunteers donate their time in so many incredible ways across our organisation – from volunteering in our shops to offering support to patients and their families and helping in our hospice gardens and offices.

The impact of our volunteers cannot be understated. They make a significant contribution, both in time and cost savings, enabling us to be even more efficient and direct more funds to the provision of our vital care service.

To acknowledge the important contribution and long-standing service volunteers gave to Hospice in 2022, we hosted a special

celebratory event for our Support Group volunteers and those working across our Adult and Children's Hospice services. We are thankful to have so many wonderful and dedicated volunteers who have volunteered at Hospice for many years, some have even been with us from the start of Hospice services!

Volunteer recruitment remains a key priority for us as a charity as our volunteer numbers reduced dramatically throughout COVID-19. Whilst they have started to improve, we hope to build on this with a dedicated volunteer recruitment campaign throughout the summer months.

Our Fundraising

The lingering effects of COVID-19 and the current economic climate continue to pose significant financial challenges for our Fundraising Teams as we navigate our way through an unprecedented cost-of-living crisis, combined with cost pressures associated with the rise in inflation, soaring energy bills, and a fall in donations.

Despite the challenges presented, we remained steadfast and committed to our efforts in generating vital income through new and innovative fundraising campaigns and events. Staple campaigns such as Hospice Walks, Big Coffee Break, Kindness Counts and Lights to Remember continued to be the foundation of our fundraising efforts.

Here are some of our key fundraising highlights throughout the year;

Lights to Remember

The easing of lockdown restrictions enabled us to facilitate our popular in-person Lights to Remember event, following a two-year hiatus. There was a huge demand for the ticketed service with over **600 guests** coming together to remember and honour their special loved ones. The online service was supported by the creation of our online virtual Christmas tree where people could leave dedications for their special loved ones. The feedback from the in-person event was overwhelmingly positive with many families finding mutual support, comfort, and hope from our special service.



Kindness Counts

Partnering with local primary and secondary schools across Northern Ireland, we continued to champion the Kindness Counts message through our targeted Schools campaign, Kindness Counts. The campaign was hugely successful with **43 schools** taking part, collectively raising a phenomenal **£30,151.95**. This is an increase of **20 schools** from the previous year and a **348% increase** in donations from **20/21**. Relationship building and networking throughout the campaign were fundamental to its success. Pharmacy Plus came on board as our official campaign sponsor, which helped to drive campaign recruitment, greater brand awareness and visibility, and delivered a greater return on investment.



Hospice Walks

Community-led events such as our annual Hospice Walks proved to be a hit with the general public. 2022 saw the return of our in-person walks with **7 scenic walks** and **3 challenge walks** taking place across the country. Hundreds of supporters came together and joined in the fun to walk in memory or in support of their special loved ones – raising an incredible **£65,000** for Hospice.



Elmer's Big Belfast Trail

To celebrate **21 years of care** at Northern Ireland Children's Hospice, we partnered with Anderson Press and Wild in Art to bring Elmer's Big Belfast Trail – a ten-week public art trail to Belfast. The event saw over **70 elephant sculptures** dotted across Belfast city centre, many of which were painted by local schools as part of the Elmer Learning Programme, and the remainder by renowned artists, generating a huge footfall and economic benefits to Belfast with **241,935 visitors** with a total event economic impact of **£12.5m**.



Livingstone Tractor Run

The Livingstone Christmas Tractor Run returned for the first time since the COVID-19 pandemic and took place on Saturday, December 31, 2022. **754 tractors** participated in the 2022 run, making it the biggest one to date. In total, an incredible **£153,415** was raised from the event and between the Southern Area Hospice, NI Children's Hospice and NI Air Ambulance with Northern Ireland Children's Hospice receiving **£51,138.40**. The Livingstone family said: "This was a great year, and we are delighted to raise this amount this year with the fantastic support of Ben Sergeant, local businesses and the public."



Madison Wright's Gala Ball

Our Youth Ambassador, **Madison Wright** swapped the classroom for the ballroom and hosted a black-tie gala ball to mark **21 years of the Northern Ireland Children's Hospice** in the Titanic Hotel, Belfast. The kind-hearted teenager raised **£38,000** to help support Northern Ireland Children's Hospice and continues to fundraise extensively for Hospice.



Northern Ireland Hospice has a thriving retail operation with **24 Hospice Shops** located across Northern Ireland. Our fantastic retail staff and volunteers helped deliver a record-breaking **£1.2m in sales** and processed **600,000 sales transactions** in 22/23. This was only made

possible thanks to the hard work, passion, and commitment of our staff and **532 volunteers** who go above and beyond to help raise much-needed funds to support the continued delivery of our services.



Our Income

The main sources of income are donations and legacies and statutory grants. Overall, Income has increased by 10.6% from £16.5m in 2021/22 to £18.2m in 2022/23, mainly due to a £1.6m increase in legacies.

Donations and legacies

Income received from donations and legacies has increased by £1.9m or 31%, from £6.1m in 2021/22 to £8m in 2022/23. This is mainly a result of an increase in legacy income received from £1.3m in 2021/22 to £2.9m in 2022/23.

Charitable activities

Income from charitable activities increased by £0.4m, from £6.4m in 2021/22 to £6.8m in 2022/23.

The £0.4m related to the statutory contracts and equated to a 6% increase, reflecting contract uplifts on the previous year, combined with overperformance against targets and funding for cost pressures in the year. The remaining increase relates mainly to funding for specific projects including funding for the Department of Health special recognition payment to staff and education initiatives.

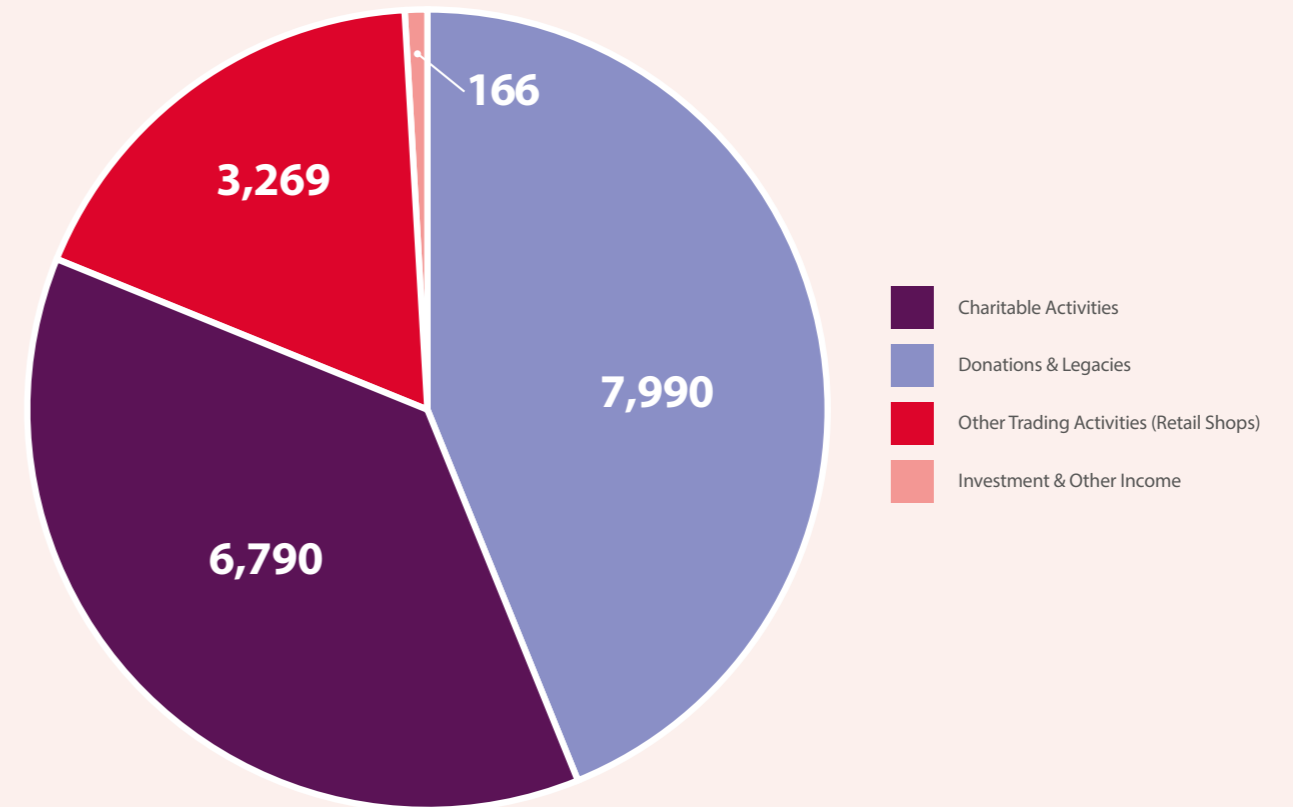
As noted in the challenges above, this Health Service funding, whilst increasing, is not at a sustainable level, and the absence of local decision-making powers is impacting our ability to influence funding allocations.

Other trading activities – Retail Shops

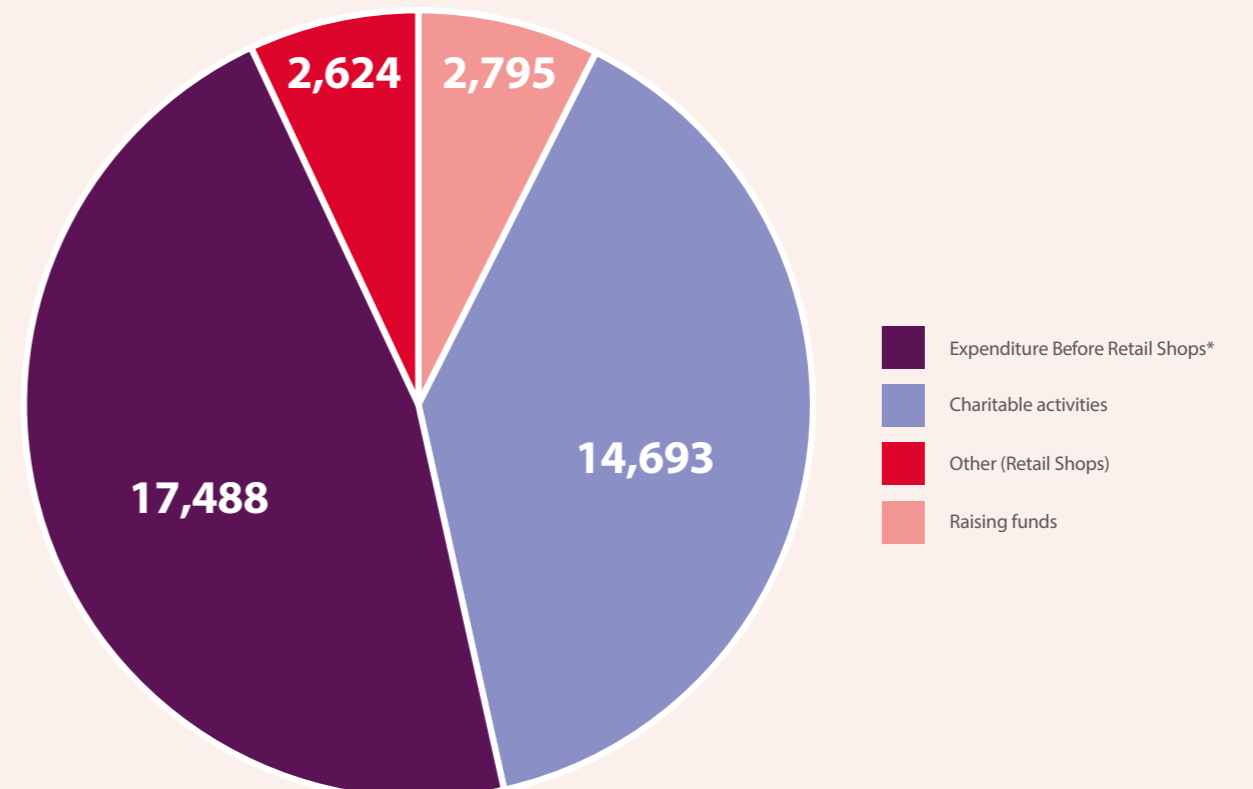
Hospice (Trading) Retail Shops were fully operational in 2022-23 versus only 11 months in the prior year, resulting in an increase in income of £0.4m, from £2.8m in 2021/22 to £3.2m in 2022/23.



Income



Expenditure





Our future plans

In the context of the significant reductions in Health and Social Care budgets for 2023/24 and the ongoing cost of living crisis, the Board and Leadership Team are reviewing the strategy of the organisation, and it is expected that this will be completed in 2023/24.

Our focus continues to be on the delivery of excellent palliative care across Northern Ireland and we will continue to develop and shape services to be as effective and impactful as possible.

Work continues to raise the profile of our work in specialist palliative care, and to advocate for access to these services for all citizens in Northern Ireland, and for fair funding from the government for this work. We work closely to support the Health Service in Northern Ireland, freeing up GP time and beds in hospital wards.

We will continue initiatives to further develop some of our already specialist qualified nurses to become Non-Medical Prescribing Nurses and Advanced Nurse Practitioners, enabling them to diagnose symptoms, develop tailored care plans and prescribe medication as they require, cutting down on unnecessary processes and significantly benefitting patients.

As the largest provider of children's and adult's specialist palliative care in Northern Ireland, we will continue to work across all available networks to influence funding and improve delivery of palliative care services.



