



**Northern
Ireland
Hospice**

IMPACT REPORT

20/21

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Our Year in Numbers



We cared for over

4000

babies, children
& adults this year.



You gave us

£8.47m

in generous
donations & legacies



A staggering

£1.2m

raised through our
Emergency Appeal

341

people were cared for in
Adult In-Patient Unit, Somerton House
which is a **14.8%** increase from the
previous year



14.6% more people supported
to die at home

Our Specialist Nurses supported **1851**
adults to have a good death, at home,
surrounded by loved ones.

We are supporting **85**
bereaved families at
Children's Hospice

The Social Work team in our
adult Hospice carried out **150**
bereavement support visits

We cared for **312** children
throughout the year.
Sadly, **27** children died at
Children's Hospice

We re-opened our

24

hospice shops across NI

It takes

£16.5m

to run Northern
Ireland Hospice



We have approx

1000

volunteers helping us
deliver our care services

3723

new referrals for our
Specialist Community
Nursing Service

169

were discharged
from our Adult In-
Patient Unit

23

wellbeing sessions
were provided for
frontline staff



We provided antenatal
support for
10 mothers



WE ARE NORTHERN IRELAND HOSPICE

We provide specialist palliative care to improve the lives and provide comfort to babies, children and adults with life-limiting and life-threatening illnesses. We support children and adults 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 hospices, Somerton House, our Adult Hospice and Horizon House, our Children's Hospice, the only one 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 nine teams of Specialist Community Nurses that deliver care across Northern Ireland. These nurses support children, adults and their families by working closely with GPs and District Nurses to identify each

person's needs and develop personalised care plans which reflect individual choice. Our Hospice at Home Service provides one-to-one nursing care during the day, evening, or night to allow family members to have a break and look after their own wellbeing.

Our Hospice Hub

Our Multi-Disciplinary Specialist Clinics allow patients living in their own homes to visit the Hospice for a day to see a range of experts who can assess and manage complex physical symptoms, as well as supporting their emotional and mental needs. Some of our interventions include physiotherapy, specialised dementia support, complementary therapies, occupational therapy, symptom management, and advice and support for carers.

Our Education Programmes

We provide learning for adult and children's palliative care in Northern Ireland. We train health care professionals' pre and post registration. Our courses span the human lifecycle, from pre-birth, infancy and childhood right through to the care of adults and older people. We have partnerships with the Department of Health, NIMDTAi and the Universities.



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.





Message from Chairman & Chief Executive Officer

History will reflect 2020/21 as one of the most challenging and unprecedented years in our lifetime. Every aspect of life was impacted by the global pandemic. With more deaths recorded during peace times than ever before the vulnerability of life was tested. But the humanity and kindness that we witnessed strengthened our resolve to serve those in need of our specialist palliative care.

Sadly, we also experienced the tragic and unexpected loss of many people due to the virus. Increasing numbers of people referred to our services were experiencing extremely complex problems and short prognoses. Society experienced a time when death, loss and grief was openly reported and observed on a significant scale.

At Northern Ireland Hospice we continued to serve local people with life-limiting and life-threatening conditions and also opened our services to those who would not recover from COVID-19. Our strategic plan activities were reviewed and prioritised with the previous year's progress providing a solid foundation for us to springboard forward at pace, demonstrating our agility and flexibility in a time of crisis.

The pandemic highlighted the value the Hospice movement brings to society, however with the challenging reality of insufficient government funding and severe limitations to our ability to generate income in the traditional manner posed an extreme risk to the charity. Together, the Board of Trustees, with the leadership team demonstrated robust risk management and due diligence throughout the pandemic, often making decisions during a time when guidance changed overnight, but always keeping a focus on safety for all.

Our people, both staff and volunteers, responded in what could only be described as selfless and professional manner. Their courage and commitment to ensure anyone who needed our care continued to receive it was simply humbling to observe. They are the heartbeat of the charity, often going the extra mile to support local families in their hour of need. The lengths and measures our frontline staff went to, as well as those roles in corporate services, fundraising, communications and marketing ensured Team Hospice remained resilient and functional throughout.

It is often said Hospice is not just a building, but rather it is a special way of caring: extending beyond walls and touching people's lives when they need supported and guided through the journey of dying and into bereavement. In this report you will read how we did this and how we responded to increased demand through innovative ways with greater collaborations and unbelievably generous support from local businesses and individuals. You will also read how our charitable objective of delivering education and furthering research was challenged, reviewed and refocused to have maximum reach and impact for Health and Social Care staff working in hospitals, primary care settings and nursing homes.



Looking forward, our goal is to recover during the next 12 months, strengthen our resilience and renew our strategy, services, and people for years to come. Northern Ireland Hospice has weathered the pandemic, successfully navigated adversity and has grown stronger to face the future with confidence and determination to deliver more specialist Hospice care to babies, children and adults living in our local communities.

We are immensely proud to present this Impact Report which was made possible by the dedication, support and generosity of so many. We are sincerely grateful to everyone who supports the Northern Ireland Hospice, together we make a difference every day.

David Clements, Chairman
Heather Weir, Chief Executive Officer

“Hospice is not just a building, but rather it is a special way of caring: extending beyond walls and touching people's lives”

OUR COVID-19 RESPONSE

We are immensely proud of how we responded during the global pandemic. It was clear from the spread of the virus from Wuhan, across the world that this was the beginning of a global change that would impact every single aspect of life. It was also obvious that Northern Ireland would eventually be impacted.

We did not wait to act and from 27 February 2020 we initiated our first communication to our people, and we kept all our stakeholders up-to-date on a regular basis throughout the pandemic.

We created an emergency response team to co-ordinate efforts across the organisation. The COVID Response Team was made up of the Chief Executive Officer, the Corporate Leadership Team, and key personnel, so that all aspects of the service could be addressed, and decisions made implemented quickly.

The primary goal of our COVID-19 response was, and remains, to keep our patients, families, staff, volunteers and public safe, minimising the spread of the virus, whilst continuing to provide the essential palliative care service needed by our local community.

We are pleased with how we have responded, adapted, and flexed all our resources to achieve our charitable purpose, ensuring our people had the resilience to continue to care. All staff and volunteers across the organisation showed the highest levels of flexibility and commitment, responding to the daily changes that had to be made.

Our people are to be commended for their dedication, spirit, and sacrifice they made. Without our staff, volunteers, and generosity of the public it would have been extremely difficult to continue to sustain the demand for care needed.



OUR COVID-19 JOURNEY



We started communicating to our staff about COVID-19

27 Feb 20

09 Mar 20

COVID Emergency Response Team created



We started making changes to our Hospice In-Patient Units to make them COVID safe

13 Mar 20

18 Mar 20

PPE Social Media Appeal



Horizon House Supported Short Breaks suspended
Old Schoolhouse cafe closed

20 Mar 20

23 Mar 20

Staff that could were redeployed to work from home



Emergency Appeal launched

30 Mar 20

06 May 20

Government announced an emergency financial package to help with our loss of income



Our shops re-open

19 Jun 20

24 Aug 20

Our Supported Short Breaks re-commence



We received Government COVID financial aid Package

29 Oct 20

27 Nov 20

Our shops close



Regular COVID-19 testing programme established

14 Dec 20

11 Dec 20

Our shops re-open



Our shops close

24 Dec 20

17 Dec 20

Our first all virtual Lights to Remember event



Our shops re-open

April 21

June's Story

June Close spoke to us last year to share her experiences as part of our Emergency Appeal. Sadly, June never got to see the incredible impact she made, as she passed away before we launched our appeal.

This is her story.

My name is June Close. I am from Belfast and have two daughters. I am (only) 62 years of age. A couple of months ago I was looking forward to 2020, spending time with family and continuing my passion as a disabled horse-rider, competing in dressage - and generally loving life!

However, my cancer is terminal. As the world worries, I find myself in a comfortable room at Northern Ireland Hospice with, perhaps days to live.

You see, over the years I suffered two strokes – it's fair to say times have been tough. It was at my lowest that I was introduced to competitive disabled horse riding and dressage. That was 14 years ago. Despite never having been near a horse during my childhood I've now won countless rosettes and trophies! There was no stopping me.



It's hard to describe the apprehension you feel when someone mentions hospice care as an option. But the pain I was suffering at home, and in hospital, was unbearable. It was horrendous for my daughters Charlene and Carol too.

Thanks to Northern Ireland Hospice, I have become a new person. Within days of arriving, I was back on my feet. I was singing with my family, celebrating my gorgeous grandson's birthday, and enjoying every single moment!

I cannot put a price on the quality-of-life Northern Ireland Hospice has given me and that's down to the care and expertise that the staff deliver, with the warmest of smiles.

Here I am amazed every day. People in the Hospice only know how to put the patient and their family before everything else. Doctors, consultants, nurses, housekeepers, café staff, social workers, and volunteers, they are all incredible people.

At Northern Ireland Hospice, I'm able to be the mum and friend to my daughters that I always was. And they can be my daughters, not just my carers. We are allowed to be a family.

The staff even helped me go on a horse-and-carriage tour recently round the local area! That was, quite simply, one of the best days of my life.

I want to stay at Northern Ireland Hospice. I know I am in good hands and that when my time comes; I will have dignity and respect.

OUR FOCUS

The driving force behind our work at Hospice is to provide comfort and relieve suffering with our specialist palliative care. We help babies, children and adults with progressive and complex life-limiting illnesses, whether it is for a prolonged period or at the end of their lives.

Our multidisciplinary team have the qualifications, expertise and experience to provide the right care, allowing their patients to live as well as possible during their illness and ensuring their comfort and dignity are maintained as they come to the end of their lives. Each person's needs are unique, they may need physical, psychological, social and/or spiritual support.

We make sure we provide the best care, because we treat the person – not the illness.

It is not only our patients but the entire family that comes under our care as they adjust and manage life with a complex illness. Our work continues after death as we continue to care for their family with bereavement support.

Throughout the COVID-19 pandemic we have continued to respond to families in their time of need. This Impact Report will highlight how we responded to COVID-19, how our services reacted and how we maintained our resilience.

WE HAVE FOUR STRATEGIC OBJECTIVES THAT OUR WORK IS FOCUSED ON:

1.

Deliver World Class Palliative Care Services in Northern Ireland, supporting infants, children and adults to live and die well in comfort and safety, surrounded by those most important to them.

3.

Live the values of Hospice, making the care of others our motivation to continually learn and grow.

2.

Demonstrate the impact and value of our vital services, raising awareness of the charity.

4.

Demonstrate organisational excellence in all our activities, at the bedside and in the boardroom.

1. Delivering World Class Palliative Care.

OUR CARE FOR ADULTS

In 2020/21 we cared for more people than ever before. The number of patients admitted to our In-Patient Unit at Somerton House increased by 14.8 percent, from 297 people in 2019-20 to 341 people.

Meanwhile, 3233 people were cared for by our Community Nurses in their own homes, an increase of nearly three percent on last year. Sadly 1,851 of those patients cared died, but through our specialist care service we were able to support them to manage their illness, remain at home and die surrounded by their loved ones. Our Community Nurses have experienced a 14.6 percent increase in deaths from last year demonstrating that our specialist care has been needed more than ever. The taboos around hospice care are well known however, we believe the positive contribution hospice care makes serves to promote our philosophy which is life affirming, giving choice, and doing all we can to ensure patients and families can be together at the end of life.

With the pandemic and the Covid safe measures that we needed to implement, the way we care for our patients and families had to change. This included staff moving to work within different teams and locations as required. The services of our day centre, Hospice Hub, had to be suspended and staff redeployed to support our In-Patient Unit and community teams, ensuring we continued to respond to referrals for Hospice care. This was done quickly and efficiently and once again our staff helped this happen with their positivity, tenacity, and dedication.

We also adapted our Adult In-Patient Unit to safely support the palliative care patients with COVID-19. The design of Somerton House allowed us to create a COVID safe environment. We divided our teams and the ward, keeping each team always separate, to allow safe care for patients and families, we closed our main entrance into the unit and removed all communal area waiting. We also introduced a new system of visiting through our gardens directly into a patient's room. Although a small change, this access route proved extremely successful in managing access and ensuring social distancing. It is through our rigorous management of infection and prevention control that we can report that within the last year we had no cases of transmission of COVID-19.

Our Family Support Team including our Social Workers and Chaplaincy team used digital communication channels to reach out to family, carers and those experiencing loss and bereavement during the pandemic.

A key challenge for us during the early days of the pandemic in Northern Ireland was the shortage of Personal Protective Equipment (PPE) before we were included in the healthcare PPE supply chain. An appeal was posted on our social media channels, asking if the local community could find us sources of PPE. The response was overwhelming, local businesses and individuals, even schools called us in their hundreds, and we received package after package of PPE to support our work. We truly thank all of those that helped us during this time.



OUR CARE FOR BABIES & CHILDREN

In March 2020, many of our vulnerable children were shielding. To reduce any transmission of the virus we made the tough decision to close our Children's Unit, Horizon House, for Supported Short Breaks.

Even though the Supported Short Breaks were suspended the Palliative and Life Limiting Service (PALLS) bed remained open in Horizon House and this was in constant use throughout the year. This allowed the Children's Services to be available for crisis situations or end of life care and provided specialist palliative care for children and babies in partnership with the Royal Belfast Hospital.

In August 2020 we made the decision to start our Supported Short Breaks again as we responded to the growing need of families receiving Hospice care. It became apparent to our team that the lack of support for families, due to cancelled respite, social work or hospital appointments had caused extreme levels of stress. This situation was further exacerbated by home schooling demands and the overall isolation of these shielding families. We also offered an extension of our Hospice at Home services in the community as well as in our Children's Unit. This gave families the space and rest to be able to continue with their day-to-day challenges. Our nurses were able to go into homes safely and parents could relax knowing that the complex needs of their child would be taken care of, and that they as a family had not been left alone. Despite the closure of Horizon House during the year we were still able to care for 312 children, support 85 bereaved families and provide antenatal support for 10 mothers.

We also worked closely with the Northern Ireland Children's Paediatric Network to develop a Regional Pathway for Palliative Antenatal Care and Support. This work has allowed many parents to be better supported when they have received the devastating news during pregnancy that their baby may have life-limiting condition. In addition, it has also resulted in an increase in the number of hospital transfers to the Children's Hospice for perinatal palliative care and bereavement support for families.

A highlight throughout the COVID-19 pandemic has been the adaptability of our teams as they strove to keep services going. A prime example is our Family Support Team. They transformed their service to ensure they could continue to engage with the children and their families, through new creative virtual methods. They set up a dedicated Facebook group for parents, with content such as storytelling, singalong sessions and art and memory making activities. There were also weekly virtual parents' evenings alleviating loneliness and isolation through interactive sessions, virtual cook-a-longs, spa sessions. The entire family was supported through virtual platforms creating sibling days, weekly bereaved support groups, family fun days and direct one to one therapeutic work.

It was this commitment to continue this type of care through different channels when physical visits and meetings were not possible that has been, according to many of our families, "a lifeline". When virtual was not appropriate the team ensured that families were not left without support and organised COVID-Safe one to one therapeutic work managed safely using PPE and social distancing.

Amanda's Story

Amanda's husband Paul died in Somerton House in 2019, leaving behind Amanda and their young son Joey. One year after Paul died, Amanda found the strength to support our Lights to Remember event at Christmas.

This is her story.

Amanda's husband Paul served in the Royal Air Force before becoming a Firefighter and Paramedic when he returned home to Whitehead. He loved football and spending time with Amanda, who first met when they both studied at college.

Amanda said: "When I look back on the life Paul led, I am thankful, and somewhat amazed at how much we did together, and how much he achieved in his career with the Royal Air Force and then as a Paramedic and a Firefighter when we came back home. For someone so young, he had an exceptional career and life.



"We shared some very special moments that will stay with me forever"



"He was a family man, a sports man, a career man and, importantly, a proud daddy. He was absolutely devoted to family life - his life changed the moment our son Joey was born.

"Paul passed away at Somerton House, where for a six-week period we got to live together - just like the teenage sweethearts we used to be - caring for one-another, crying, laughing, and preparing for the journey ahead.

"Paul would have liked to have stayed at home for his final days, but it just wasn't possible. The Hospice, however, made a home-from-home for us."

She added: "The Hospice itself, and the doctors, nurses, housekeepers, volunteers, social workers - actually everyone there - were an extended family for us. Even when things were at their darkest, there was someone there to talk to, or to lend a hand.

"At times it was hard, but it was also time that was so precious - I don't think we could have got that time while caring for him at home. We were able to talk about so many things, we planned for his funeral, and for Joey's future.

"We got to grieve together, and that's not something I would have thought possible. We shared some very special moments that will stay with me forever.

"We didn't want to leave one another, and we got to do that at Hospice. That would not have been possible anywhere else."

Amanda and little Joey spent Christmas 2019 without Paul. It was an extremely difficult time for them. Together, they attended the Lights to Remember event.

"It was an unbelievable experience for us. Being part of the Lights to Remember event last Christmas, was very important to us and I am very happy and proud to have played a part in it. I know how special this event is for local people like my husband who received the best care and the utmost dignity and respect in his final days at Hospice."

2 Raising Awareness of Hospice

Raising awareness of our services was never more important than in the year that our usual methods of engaging with stakeholders were obsolete. Our focus became razor sharp, many of our fundraisers were placed on furlough, so the burden of generating income became the focus of the Marketing and Communications teams.

The Hospice was facing a significant risk to income generation, but our teams rose to the challenge. Within weeks of lockdown measures being implemented in Northern Ireland we had launched our Emergency Appeal, “Now More Than Ever”. This integrated marketing and communication appeal was the first of its kind for us and utilised a variety of creative content to engage with the local community. We developed our Hospice storytelling alongside messages of support from our ambassadors and celebrity friends of Hospice, a direct mail campaign that was issued to 25,000 households, as well as radio, print, outdoor and television advertising.

Following the Emergency Appeal, we developed new and creative ways to engage with our donors and challenged them to support us in any way that they could. It accelerated our move to more content driven campaigns in the digital world, so we transformed our fundraising into digital or virtual campaigns, allowing our supporters to continue to take part, from the safety of their own home or as social distancing restrictions allowed. Our frontline care team directly contributed to the storytelling of Hospice, developing their own content which was transformational. Not only did our multi-disciplinary team get involved to raise awareness but our families reached out to help encouraging support of Hospice through their personal stories.

We scaled up our traditional direct mail campaigns to reach more homes across Northern Ireland and used social media, our ambassador network and TV and Radio advertising in a way that we never had done before.

Throughout the COVID pandemic, we have witnessed many acts of kindness and generosity from our local community, business community and organisations, without their support we would not be able to continue to deliver our vital care services.



Conor Murphy MLA - Minister of Finance visiting the Hospice

Support Groups Role

The Hospice has a long history of engagement with local communities via our support groups. During the pandemic it was extremely challenging for the Hospice Support Groups to implement their plans for fundraising. Many continued to creatively raise funds for Hospice, for example, the planning and production which went into creating “The Big Night In”. An amazing night of online entertainment from acts across the world, organised by Ballymena Support Group. The lengths which our amazing supporters went to support the Charity encouraged all our staff at the frontline, who remain thankful for the contribution that fundraising volunteers make.



Seán Óg Mac Corraidh

Norman Mawhinney

Between the 4th and 9th May 2020, Norman, who is now 74 years old, walked and ran 73 kilometres – one for each year of his life - by doing one thousand laps of a 73-metre course around his house and garden. Norman raised over £10K for Northern Ireland Hospice through a JustGiving fundraising page.



Norman Mawhinney

Seán Óg Mac Corraidh and family

Seán Óg Mac Corraidh and his family raised over £17K through a Facebook fundraiser by live streaming a Traditional Irish Music ‘Lockdown Session’.

Lights to Remember

Lights to Remember is one of the most important campaigns and events in the Northern Ireland Hospice calendar. We made it a priority to make the service available to as many of our supporters as we possibly could and were extremely grateful to Stellify Media who produced the entire service for us, capturing the emotion of the annual event and presenting it in a 30-minute film which allowed us to stream it on our website, YouTube, social media and Belfast television station NVTV. We transformed how people engaged with this campaign by using an online platform where our supporters could remember their lost loved ones by adding a light along with a message and picture to our virtual tree. The campaign raised more than £336K.



Lights to Remember



Sir Knights

Sir Knights

Sir Knights, in County Armagh, raised £17K for Northern Ireland Children's Hospice. During lockdown, the Sir Knights launched a county appeal for the Children's Hospice after hearing about the impact the pandemic was having on our fundraising activities of Hospice. The funds were raised through the local community and their willingness and generosity to help.

Dennison Commercials

Unfortunately, the COVID pandemic halted many of Dennison's charity fundraising plans, but that did not stop them from honouring their initial pledge of raising £50K for the Children's Hospice as part of their 50th anniversary celebrations. This incredible donation came at an extremely crucial time for the Hospice and enabled us to continue to sustain our vital services.

Bob & Berts

Despite countless lockdowns and restrictions causing havoc with their fundraising plans, our Corporate Partner, Bob & Berts, brought joy to children and families across Northern Ireland during the Christmas period by raising over £22K to help support the vital work that we do across the province.



Dennison Commercials



Bob & Berts

Hagan Homes, Vanrath and Pinnacle

Each sponsored a Hospice Nurse's salary throughout the year. Those partnerships have made such a practical difference, enabling us to strengthen and sustain our Hospice care in the community.

Retail

Our vital Hospice shops were closed for 27 weeks of the trading year and the normal reliable income stream was lost. However, we identified savings in all areas possible, we received Government assistance and we were fortunate to work with our landlords to mitigate as much of the impact as possible. This intense work led to a better financial outcome for the retail branch than could ever have been expected. During the time that shops were re-opened we were able to do so safely with clear COVID safe measures that reassured our customers and ensured that everyone within the Hospice Shop environment remained safe.

Our Partnerships

Our Chief Executive and leadership team worked collectively with the other Hospices to gain financial support from the Northern Ireland Executive to sustain our services. Through engagement at all levels, we have strengthened relationships with Executive Ministers, MLAs, MPs, Councillors and Civil Servants. This bodes well for ongoing and future discussions in relation to fair funding and improved integration of Hospice services in Northern Ireland.



Theo's Story

Theo comes to Horizon House for Supported Short Breaks; he celebrated his fourth birthday in July. With blonde hair, blue eyes, Theo is your normal little boy - curious, affectionate, and a force to be reckoned with! However, Theo and his parents, Edel and Brett, have a lot more to deal with than other little boys his age.

This is their story.

Theo's genetic condition is so rare that it hasn't been fully diagnosed yet and the only other similar case is in Arizona in the United States. Edel and Brett became worried when Theo wasn't meeting the normal milestones for his development at around 4 or 5 months old, and sought help, but since then they have helplessly watched his condition continue to progress, with new symptoms, such as his epilepsy appearing all the time.

Edel and Brett told us, "Theo's condition means that he regresses as he is growing, we have watched him lose the abilities that he has learned - nine months ago we could put him in the car and head off for a visit to his Nana, now he needs an oxygen tank, a stats monitor and so much other equipment - we've actually had to buy a van to hold it all.

"When Theo is in Horizon House, it is the one and only time when Brett and I can relax."

Our families don't live near us, so sometimes we can feel a bit isolated, sometimes it feels like Theo's good days are becoming further and further apart." Brett said: "Essentially, it's about getting through each day, managing Theo's symptoms and helping him to be as happy as he can be."



The pandemic has been particularly hard on Edel and Brett and a recent stay at Horizon House brought a realisation to them that they "hadn't taken time to breathe" in six months. Edel said: "When we went to Hospice for a supported short stay, it was only then we found time to sit back, and I thought, wow, what have we just been through?"

"There's a lot more involved in managing Theo now and knowing he can go to Horizon House to play, to engage and escape, is great for all of us. It's not just a break for us but Theo is there learning new things all the time. It's a great place for him to be.

"When Theo is in Horizon House, it is the one and only time when Brett and I can relax and be safe in the knowledge that if he happens to have a seizure, he's in great hands and far better equipped than us.

"Hospice is our lifeline, it really is. Theo loves going there - we can see it in his sparkling eyes. At the start when we went to Hospice, I couldn't imagine leaving him with anyone else, but they look after him so well and he loves it so much. It's like family - I trust them that much."

"Hospice is our lifeline, it really is"

3 Living the values of Hospice

Our people have always been our priority, however this year our people have truly been the heartbeat of the organisation and we are thankful and grateful to each and everyone.

There were many new processes to be developed and implemented quickly at the beginning of the year. We put in place a COVID tracking spreadsheet to monitor any symptoms, testing and results on our staff and ensure speedy backfill of the absences that we had to contend with. We were grateful to be included in the Health & Social Care weekly testing programme for staff and volunteers at the frontline. This allowed a greater degree of confidence, regarding any potential spread of the virus and our follow up actions. Following on from the regular testing programme we then moved to encouraging and monitoring the uptake of the vaccination programme.

The organisation's leaders at all levels worked hard to maintain staff and volunteer engagement during the pandemic. There is no doubt that our managers had to reset expectations and adapt coaching leadership styles as many of our team members grappled with, not just working from home but with home schooling and IT difficulties, time and space to work.

While we put in place both new policies, guidance and flow charts to enable a smooth transition to a new world of work, we still had our attention on the People & Development Strategy we had laid out before the pandemic. The pandemic has been a great opportunity to develop the Organisation Development work we had started in 2019, redesigning jobs and creating a coaching culture in the organisation – all this has been accelerated by the need to manage differently and a number of our managers and leaders have benefitted from personal coaching and mentoring programmes.

The impact of working through COVID-19, working with PPE and social distancing with increasing numbers of end-of-life patients and the constant threat of the virus has impacted our Care Team staff, emotionally, psychologically, and physically. We designed and delivered training programmes that would support staff, from therapeutic support via de-briefing sessions, to managing sleep and anxiety in uncertain times,

building resilience, mindfulness and managing emotions. We are thankful to the team at INSPIRE who assisted us. Recognising the dedication, commitment, and incredible efforts from all our care staff, we renewed our focus on wellbeing and recovery in a number of ways.

In October 2020, we introduced 'The Big Time Out', a day dedicated to different aspects of wellbeing each week for a total of five weeks supporting them to refresh and renew.

A working group of staff introduced the concept of 'The Snug' and 'Wobble Wall' in Somerton House. A meeting room transformed into a place where staff and volunteers can avail of quiet time when they need it the most. Reflecting and recharging from the emotional and challenging aspect of their caring roles. We reinforced the message that it's okay to not be okay, encouraging our staff to talk about how they were feeling. Our Board of Trustees supported staff to have up to two additional wellbeing and recovery days, which was greatly appreciated.

We were successful in applying for a grant by the Burdett Trust for Nursing through a COVID-19 Nursing Resilience programme. This has funded a comprehensive education and therapeutic offering for all care staff including courses to enhance personal and emotional resilience, stress management, sleep and mindfulness, bespoke leadership programmes and individual and group support through debrief and specialist interventions.

We also delivered professional development programmes which included career pathways for our care staff and the 'Emerging Leaders Programme'. We invested in our employee benefits schemes, with opportunities for staff to make savings on private health care, technology and car leasing, all which became operational in 2021.



(Left to Right) Charlie, Maeve Loughran, Lorraine Crawford, and Esther

VOLUNTEERS

These challenging times had an enormous impact on our volunteers, and we had to limit the numbers coming into our buildings and stand down those who helped with functions, such as fundraising and shops. A sizeable number of our volunteers are categorised as vulnerable, so they took time out during the pandemic.

Unfortunately, the number of our volunteers decreased by two thirds between April 2020 and April 2021. The loss of volunteers during this period presented a huge challenge as we rely so heavily on their input to our frontline services and meant that our staff had to take on some of that work, on top of the already difficult jobs they were doing.

We stayed in regular communication with all our volunteers throughout the pandemic and discuss regularly what is happening and when

services will resume, we really look forward to welcoming these amazing, committed people to Hospice in the coming months.

This year we developed a Volunteer Strategy and are working hard to create a volunteer service that meets the changing needs of our service over the next few years. As we move forward, we will strengthen the resources to support volunteers to join and serve with the Hospice.

Colleen's Story

Colleen is living with cancer and has received care from our Hospice Community Nurse Specialists.

This is her story.

Colleen Ward lives in a farmhouse nestled in the beautiful Dromara hills at the foot of breath-taking Slieve Crobb in County Down. It is there she wants to remain.

It was 17 years ago that Colleen was first diagnosed with cancer. After six major surgeries, and battles with Sepsis, MRSA, and Pneumonia, she was cancer free, and stayed that way for 10 years. In the summer of 2020, Colleen was again diagnosed with cancer and was told there was no treatment for it. She was adamant she would die at home and her wish will be made possible by our Community Nurse Specialist service. Her specialist nurse is Oliver Mallon.

Colleen, who enjoys spending time with her grandson Jackson, said: "I was quite surprised that Northern Ireland Hospice was able to provide care for me in my home.

"I had no idea of all the things that Hospice can do and how many different services it has. But the one thing I do know is that I would have been lost without my community nurse, Oliver. His help and knowledge have allowed me to stay at home with my family, which is the most important thing for me.

"I don't know how long I will be able to stay with my family but with the Hospice helping me, I will fight until the very end."

When Colleen was diagnosed with cancer for a second time, she was asked if she would like palliative care while in the company of her sister, a nurse. She added: "It was my sister that shouted 'yes' to palliative care and that is when the Hospice came into my life, and when Oliver first came to see me. "He sat down with



me and explained how he can help, how he would work with my doctor to get me the right medication to manage my pain and any of my other symptoms.

Because of my history, mine is a very complex case but Oliver has so much knowledge, and he notices everything.

"I can't even try to hide any pain or symptoms from him, he knows exactly what to look for and how to treat it. When he was leaving after his first visit Oliver provided all the Hospice contacts and said, 'don't ever be afraid to call anytime, do not be sitting here in pain, just call and I will help'. Ever since Oliver started looking after my condition, I have not had any pain! I honestly do not know what I would do without this care.

"I am so lucky to have my family around me at this time. My husband Alister and I have four grown-up children who have been very helpful, and my grandson Jackson (3) brightens up my days. "When we had snow last winter, Jackson came over to play. The fact that I could go out into the garden and have fun in the snow means the world to me."

"I know it was hard on my family to know that my illness was terminal. But the main thing is that I am with them now and I feel good, so I will keep going. I am at home, and with the help of the Hospice, that is where I will stay."

4. Demonstrate organisational excellence

When the pandemic hit all Health and Social Care training and education was suspended so that staff could be deployed to the frontline. This had a direct impact on our ability to continue the operations of the Palliative Care Learning Academy (PCLA).

Staff who could be redeployed in Hospice frontline services from the PCLA, were, whilst others were furloughed. As the pandemic continued, it was evident that the ambition of the Palliative Care Learning Academy would not be achieved, and the Board of Trustees agreed to stand down the Academy and review how we would deliver education in the future. This was a difficult decision which resulted in changes to the staff delivering education.

Whilst the PCLA was closed our education programmes became ever more relevant with more people dying from COVID. In November 2020, the Department of Health asked us to deliver three bespoke education programmes to nurses working in the Health and Social Care Trusts. This successful partnership has resulted in improved collaborative relationships with the Health and Social Care Trusts and commissioned programmes for training and development. Our focus was on better communication and improved symptom management, this was supported by our medical consultants, who trained GPs and hospital doctors via Zoom.

Our Care Team absorbed all requests for education, and this has allowed us to reinstate Hospice education and the partnerships we have. In addition, we have worked with the nursing home sector to equip their staff with the knowledge of palliative care. This will continue, as will our role as a regional training centre for pre and post registration health care professionals.

When the pandemic struck it emerged that our IT and Digital Strategy needed to be fast tracked. An intense period of development was needed to implement the structures needed for homeworking and to keep the organisation working effectively. This work whilst delivered in accelerated pace, has moved us to a point of readiness, where we have confidence to advance our digital transformation. Our people moved seamlessly to working with new technology which promoted teamwork and improved communication. The Hospice demonstrated innovation during a crisis, which upon reflection, has paved the way for continued transformation and has created a positive outcome for the Charity.



This photo was taken before the COVID-19 pandemic

Sebastian & Sophia's Story

Nicole and Matt Rooney are parents to Sophia (9) and Sebastian (5), two beautiful children cared for by Northern Ireland Children's Hospice. Sophia has been attending Horizon House for the past eight years along with younger brother Sebastian since he was born five years ago.

This is their story.

Nicole said: "When I was pregnant with Sophia, everything went well, then two weeks after she was born, she started to have seizures - and lots of them. We kept taking her to the hospital, but they could not find anything wrong.

"We literally spent every day for weeks coming home and going straight back to the hospital because we knew something wasn't right. During one visit to the hospital, Sophia had a lot of seizures, and was sent for testing, then we received the diagnosis that she had Polymicrogyria. "Polymicrogyria is a brain abnormality, it means some brains have too many folds so they cannot process information as normal and impairs ability.

There are different types of Polymicrogyria, but it is very severe when it affects the entire brain, this is the condition that both Sophia and Sebastian have. It causes severe problems such as epilepsy, developmental delay, and muscle weakness.

"I cannot lie - the first few months after Sophia was born were difficult, I was 19 years old, and Matt was 24. When Sophia was six weeks old, she was having 50 to 60 seizures a day. It was a scary time for us.

"When Sophia was just four months old, she needed an operation on her throat to help her breathing. She spent her first Christmas in hospital. Sophia also stopped feeding normally. She had a tube inserted into her tummy to

receive food, fluid, or medication directly, although it sounds terrible, Sophia has a better life this way. "It was after her time in hospital that we were first introduced to Hospice. Like many parents, after Sophia's time in the hospital when we nearly lost her, that first conversation about Horizon House was very scary for us. We thought - like many people do - that Hospice was only for children who were dying - we were so wrong.

"We visited Horizon House and we instantly felt that our lives were changing for the better. It was amazing! From the minute you walk in through the doors all your nerves or worries disappear, it is such a special place. When we started visiting with Sophia, we would all stay as a family and that is really what we felt like - a family with nothing to worry about except resting, playing, and having fun, and with the bonus of having our dinners made for us too! They take care of everything, and I cannot even express how much that means.

Sophia also has spinal scoliosis; her hips are dislocated which means you must be so careful when turning her over. She cannot sleep on her back anymore, she can only lie on her side. To know that it's these types of issues that her Care Team know about and can manage with their expertise really gives me peace of mind - which is something that does not happen often in my life!

"Matt and I NEVER switch off and relax. We constantly think about the next medication, or we are monitoring any new or changing symptoms, or getting ready for the next feed. When we go to Horizon House, all of this is lifted from our shoulders. Nicole and Matt thought about growing their young family.



"We can only do this with the support of Children's Hospice. We don't have a family circle that can help, so without Hospice we would be alone, and I don't believe we could do it without them."

Given their experience with Sophia, they tested to see if her condition was genetic. Results showed that it was not genetic and so, with confidence, they planned for a second child. Nicole's pregnancy went well but when Sebastian had an MRI soon after he was born, it was discovered that he had Polymicrogyria just like Sophia.

Nicole added: "Horizon House stepped in and helped again as they looked after Sophia to give us a bit of support. It just showed us that when we needed them, they were there for us. Sebastian and Sophia now come to Horizon House together, and they just love it.

They are so close as brother and sister, but they have their own personalities. Sophia responds to sound, and she will respond to her name, but especially if you sing it! "She loves hearing 'kissy noises' and strangely loves the

noise of coughing - obviously with Covid we had to stop pretending to cough quickly - now we listen to YouTube coughing videos instead - who knew - and she laughs and laughs. On the other hand, Sebastian really loves his time at Hospice, he loves getting to use the multi-sensory room and swimming in the hydro pool.

"Matt and I need to have the energy every day to care for their medical and physical needs and we also need the energy to make Sophia and Sebastian laugh and discover new things to share.

"We can only do this with the support of Children's Hospice. We don't have a family circle that can help, so without Hospice we would be alone, and I don't believe we could do it without them."



INNOVATION DURING A CRISIS

Whilst it may not be the opportune time for every organisation, we quickly realised during the pandemic that we had a unique opportunity to try new ways of providing our care. Many of our traditional methods of care were now restricted but people still needed our help so over the last year we have introduced new service models to meet current and future needs.

We strengthened our partnership with the Belfast Health & Social Care (HSC) Trust to introduce a Rapid Response Hospice Service. This service allows us to provide:

- a single point of access and triage for all Belfast specialist palliative care referrals in the community.
- consistent and early categorisation of complexity and the type of service needed for each referral.
- a dedicated Community Consultant with overview of all referrals entering service.
- the ability to provide same day response by a specialist nurse.
- joint specialist nurse and medical domiciliary and virtual consultations; and
- increased ability to employ complexity allocation approach across wider Belfast HSC Trust area.

Our Rapid Response team carried out 332 urgent visits to patients, when and where they needed our service the most. More than 100 joint visits by a Hospice doctor and Specialist Nurse were carried out to assess and manage patients, matching individual patient's needs to the high-level skill set of the Hospice staff.

These visits have made all the difference to people suffering with complex conditions. Rather than continue to suffer our collaborative way of working ensured that the issues they were facing were resolved to allow their condition to be managed and as much as possible allowed people to remain at home, where they wanted to stay.



WE ALSO STRENGTHENED OUR RELATIONSHIPS WITH THE NORTHERN HSC TRUST. WE EMBARKED ON TWO PILOTS:

1.

We introduced a Hospice Specialist Nurse Facilitator to support collaborative working, focussing on supporting nursing homes in Mid Antrim. The aim of this project is to develop, strengthen and enhance palliative and end of life care service provision and delivery in these settings.

2.

We also introduced a Specialist Palliative Care Social Worker to the Loughside Specialist Community Team. The pilot enhanced our current Specialist Palliative Care service as it allowed for social work visits within the patient's home, pre and post bereavement support and supported a multi-disciplinary approach to patient care.

In addition to the pilots and the development of the Rapid Response Service, we introduced a multi-disciplinary outreach service. This service complemented the Medical and Nursing input by providing 246 interventions from Occupational Therapy, Physiotherapy, Social Work, Complementary Therapy and Chaplaincy Team. Through these services we believe we can provide our patients and their families, a better quality of life, improved support and reduced admissions to hospitals.

OUR INCOME & EXPENDITURE

Last year we saw a reduction in the income we were able to raise through our fundraising, even though our supporters continued to give as generously as they have always done. We are so grateful to each and every one of our supporters.

Our Emergency Appeal was rolled out very quickly in March 2020 and was extremely successful, without it we would have faced a much larger gap in funding.

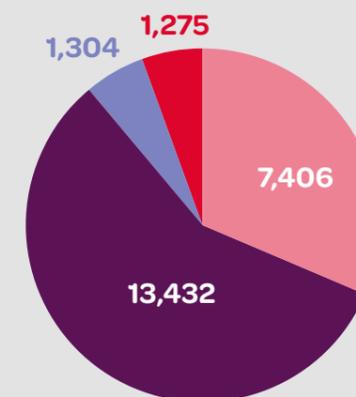
We were also grateful to receive financial aid from the Government to support us during COVID. However, we know that both the Emergency Appeal and the financial aid were unique events that will not be repeated in the future.

This leaves us in a precarious position as we move forward, the reserves we have from the financial aid will support us through 2021-22 but we must look to develop new income streams to sustain our services for the future.

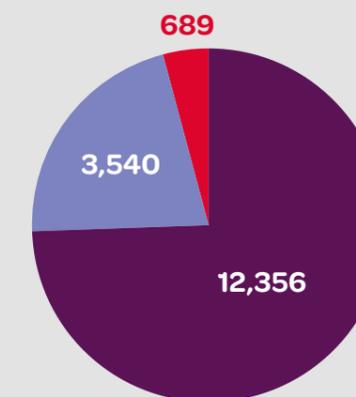
Expenditure

The majority of our expenditure is focused on our people costs and last year we made the decision to increase the wages of our Care Team in line with the NHS salaries.

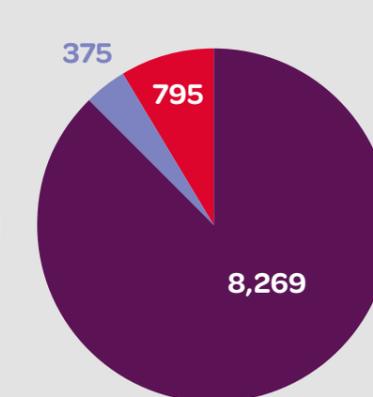
INCOME - (£000'S)



EXPENDITURE - (£000'S)



COVID FUNDING AND GOVERNMENT FUNDING SUPPORT - (£000'S)



- Donations & Legacies
- Pay Costs
- COVID Funding
- Charitable Activities
- Operating Costs
- Hospice Furlough
- Trading
- Depreciation
- Retail Furlough & LRSS Grants
- Investment & Other Income



Ben Dickinson, 10, who ran one mile every day in March and raised over a staggering £7,000



Chloe Stewart and Tighearnan Corbett, raised £5,352.20 in memory of their beautiful baby son Che.



McLean family and friends who raised £8,352.07 through their 10K Hospice Walk in memory of James McLean.



Pavers Foundation awarded Northern Ireland Children's with £2.5k grant to purchase iPads to ensure children at Horizon House can stay in touch with their families.

WHAT'S NEXT

As we move forward into 2021/22, we look forward to the return of 'normality' that could see more face-to-face interaction and hopefully a time when our care can once again offer a hug in a time of need. However, we have learned much as we have worked through the pandemic, and we will use these lessons to guide us as we move forward.

Partnerships and collaboration will remain a core part of our work as we move forward as we have seen first-hand the difference that increased partnership can make to people's lives in Northern Ireland. We will continue to develop collaborations such as the Rapid Response Service to provide immediate care to those who need it but to support the Health Service and reduce future pressures. We will strengthen our networks, especially with the Regional Paediatric Palliative Care Network, supporting vital work around antenatal palliative care and end of life care for babies and children.

Many people have remained at home in the last year even when very ill, part of this reason has been the fear of COVID-19, but we know for many, home is the preferred place of care. We have a strong community presence across Northern Ireland, but we must increase awareness of this service so that people understand and have no fear of accepting help from a Specialist Hospice Nurse. This communication and engagement work will be key to our partnership working and changing perceptions of Hospice care.

We will provide expertise in our field, assisting other organisations to better understand and manage general palliative care for their patients. This will allow our specialist palliative care to be utilised when it is most

needed. We will also invest in our people so they can become more autonomous in the delivery of their care, allowing our specialist nurses to become Non-Medical Prescribing Nurses and Advanced Nurse Practitioners. This will allow them to diagnose symptoms, develop tailored care plans and prescribe medication as they require, cutting down on unnecessary processes. This will have immense benefits for our patients, as well as freeing up time for GPs who continue to face huge workloads.

Through the work to minimise the financial impact on our Hospice shops we were able to retain our retail footprint. Discussions throughout the pandemic has allowed new opportunities to be realised, the first of which is the prime location for the new Bangor Shop. We look to transform our shops to become a 'destination', the high street will now need to be able to compete with the digital world and we will position our Hospice shops to be at the forefront of this competition.

Our focus for 2021/22 is very much on our resilience and rebuilding our services and our priorities are:

1. Develop 2022 - 2025 Strategic Plan
2. Expansion of Specialist Palliative Care MDT in the community
3. Deliver Hospice Education Programme
4. Sustain financial stability and grow income
5. Understand and promote the Hospice Brand
6. Develop value added partnerships
7. Stabilise, support and develop our people to and be their best
8. Progress organisation and digital transformational plan



