



St John's Hospice
St John & St Elizabeth Hospital

Impact Report

2023







A message from our Chief Executive

2023 has once again, been a busy year for our hospice and my first as Chief Executive. It has come with its challenges not just for St John's but for the sector in general. Despite this, we were able to achieve so much and continue to draw up exciting expansion plans. Our achievements have undoubtedly only been possible through the sheer dedication of our staff and volunteers, and the generosity of you, our wonderful supporters and partners.

This report has been written retrospectively and at the time of writing this message, I am delighted to report that the all-new St John's Hospice Wellbeing Centre has opened its doors to patients. The new centre marks the start of an exciting new chapter for our hospice. Thanks to your kind generosity we now have a physical building which reflects the gold standard of care we provide and for which we are known in the community. It also reflects our commitment to the physical and mental health and wellbeing of not only our patients and their loved ones but also our staff.

The opening of the centre is the catalyst to the next phase of ambitious plans. Our priorities over the next five years are to increase our community nursing provision to 8 am – 8 pm, seven days a week, 365 days a year, extend Inpatient Unit admissions to seven days a

week, launch complementary therapies in people's homes, update our patient vehicle fleet, and invest in the sharing of expertise amongst our staff and across the sector.

Over the next five years, we plan to expand existing services into boroughs where there is currently no provision of this kind. This includes the potential expansion of our child bereavement support, the creation of a community hub, as well as the expansion of our Hospice@Home service. This will not only ensure that our specialist support can reach those who need it but that people living with life-limiting illnesses and their loved ones are given more choice in how and where they are cared for.

Thank you for helping us be the beating heart of our community and ensuring that we can continue to be there for all those who need us across North Central and North West London.

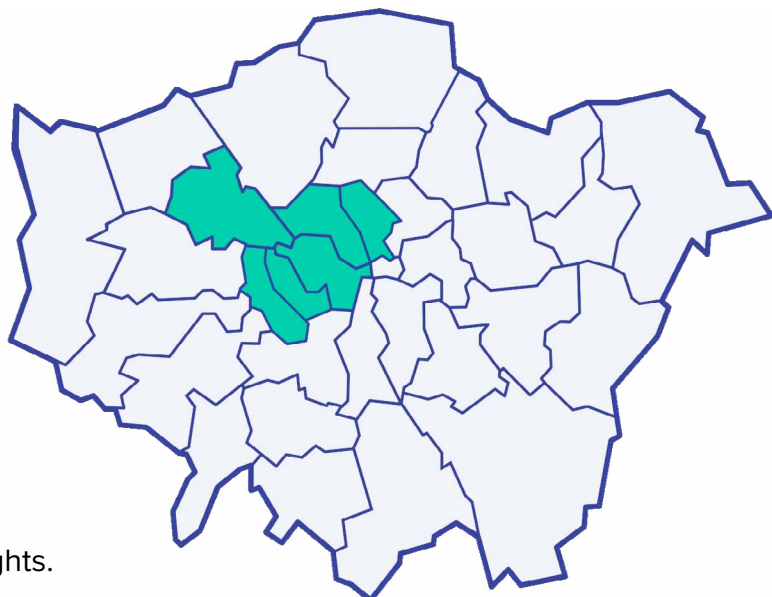
Kind regards

Simon James

Our year in numbers

4,272

patients, family members and carers accessed our services across North Central and North West London.



235

patients benefitted from our inpatient care across 3,651 nights.



1,564

visits to our Day Care Unit were made by 67 patients.



1,728

complementary therapy sessions were provided for patients, family carers and bereaved loved ones.



1,609

home visits and 5,370 telephone consultations were made by our Community Specialist Palliative Care team to a total of 205 patients.



21,193

hours of care were provided by our Hospice@Home team to a total of 116 patients.



£2.07 mil

generously donated by 3,955 individuals, schools, community groups, trusts, foundations and corporates.



2,109

journeys were carried out by our ambulance drivers.



82

children and young people benefitted from bereavement support.



351

patients and families were supported with practical and emotional support from our social workers.



645

patients were supported with specialist Lymphoedema treatment.



120

volunteers supported our hospice across a range of clinical services, retail and fundraising activities.

Patient stories

Veronica and Riccardo's story

38-year-old Veronica and her husband, Riccardo, moved to the UK from Italy just a few months before Veronica received her cancer diagnosis. The couple found themselves in a new country and separated from their usual support networks when, in their own words, their “world was turned upside down.”

“It was a lot to face, and the hospice helped ease that pressure, that initial shock of the diagnosis and how our lives were going to drastically change overnight,” Veronica explains. “One month after my diagnosis, we were supposed to be getting married. So, it felt like the worst timing. We were planning on having a family, future adventures, and all that you think of when you are newlyweds. But everything was put on hold. Quickly after my diagnosis, I also had to stop working, as did Riccardo as he needed to care for me.”

“When I was discharged from a period in hospital I could barely walk from the pain, and I was quite weak, so the St John's Community team came to us at home. As well as being a source of pain and symptom control, our community nurse discussed the new situation we found ourselves in, the medications I was now going to be on, setting up the equipment I would need, and organised visits from their therapists. They also referred us to the day services at the hospice and made sure that in those months when I struggled to walk, the ambulance came to pick me up, so I never missed a week.”

Riccardo goes on to explain, “When you are someone's primary carer, you are together 24/7, and sometimes that's not easy. I would never have expected that as a carer I could also have received so much support, have my own time to chat with their team and benefit from wonderful therapies like the massages.”

“When we first found St John's, we were in complete disbelief. We thought, how on earth can this amazing care, be free? We kept saying to one another, what can the catch be?” Riccardo laughs as he explains. “But of course, there isn't one. It's been a huge help at a time that has been honestly incredibly difficult to accept, process and cope with.”

We are delighted to report that since sharing their story, the pair made their long-awaited return home to tie the knot, surrounded by their family in Italy and are now making plans to return to work.



“St John's helped us realise we weren't alone and that there was this amazing community we were a part of and that we could be supported by.”

– Veronica, patient.

Maria's story

92-year-old patient Maria is a remarkable woman who has dedicated her life to looking after others and is a huge part of our community. Having moved to the UK in her twenties, Maria has worked as a cleaner, housekeeper, and nurse, as well as volunteering for organisations that help combat loneliness experienced by older people.

During the COVID-19 pandemic, Maria's health began to deteriorate leading her GP to refer her to our hospice and in particular, our community outreach services, knowing the significant impact these could have not only on her physical health but also her mental health and wellbeing.

"I remember my doctor telling me, 'I think we should look at referring you to St John's Hospice'," Maria recalls. "I think she could see I was worried from the look on my face, because she said, 'It's not because you're dying Maria. They are a local organisation that will be able to help you so much more.' What followed all sounded so wonderful."

"She told me about having a nurse who could visit me at home to help get my symptoms under control, help sort equipment I needed and things like that. She also told me about the day services, where I'd be able to have therapies but also companionship."

"When Stuart the nurse came to visit me at home for the first time, I was so impressed. He managed to get so much sorted, so efficiently. After this first visit, he also referred me to get support from his colleagues in the Therapy team. Just a few days later someone came over, and assessed me at home, looking at how I got in and out of bed, my chairs and everything like that. She then recommended what I would need. Not only that, but she got on to all the right people to help me get it, I just couldn't believe it. St John's is a true blessing."

"As well as that I go to the Day Care Unit. Where we have music, we laugh, and we chat all day long. I have my friends. It's a wonderful place, a true community. Everybody loves coming and we're all so grateful that a place like this exists."



"Some days I feel so lonely at home. It is depressing. When I walk in here, it is like walking into heaven." – Maria, patient.

The impact of our services

Ambulance service

Our ambulance service, which is a unique service in London, enables us to safely transport our patients to and from our hospice as well as any of their external medical appointments. In particular, the ambulance aids the admission and discharges of our Inpatient Unit and is made available to our day service patients with reduced mobility or access issues. Without it, many of our patients would not be able to access these services.

In 2023, our team of ambulance drivers carried out 2,109 journeys. This included 1,911 journeys for day service patients and 198 additional journeys such as transporting patients in for lymphoedema treatments, complementary therapies, and inpatient care, as well as to their external hospital appointments.

Our ambulance fleet is made up of three vehicles, a passenger vehicle, a stretcher vehicle, and a 5-seater. Our stretcher vehicle went out of service in May 2023 meaning we were unable to cover as many inpatient journeys compared to the previous year. The new vehicle is set to arrive in April 2024. We are making it a priority to update the other two vehicles in our fleet in 2024, ensuring the service remains accessible for patients who depend on it.

Bereavement support

Our bereavement support begins from the initial diagnosis and continues throughout a patient or their loved one's care. Our adult bereavement support is offered to family members, carers and friends who have lost someone under the care of St John's Hospice wherever they live.

Towards the end of 2022, thanks to donor support, we successfully recruited for a range of roles across the Social Work and Bereavement team also increasing the hours of current team members to support the increase in referrals. 2023 saw us having a complete team with additional posts including a part-time Adult Bereavement Coordinator/Counsellor, Administrator and Team Lead.

Having made our Child Bereavement Specialist full-time in September 2022 and with the enhanced capacity of the team, the number of children and young people supported continued to rise in 2023. In total, 82 individuals benefitted from 1:1 counselling, peer support groups and activity sessions. These activities, which coincide with the school holidays, create opportunities for the children and young people to meet up with peers who have also experienced loss. In 2023, these included a day out to the Young V&A Museum, a theatre trip to see the Snowman and sporting sessions with the team at Lord's Cricket Ground.

“The surviving person and their journey with the hospice is so important. Being able to come here has been such a help. I'll always be grateful for the incredible care you gave my husband and the continued support you give to me and my children.” – Diana, bereaved relative.



Our child bereavement support is currently available to those living or educated within the borough of Westminster or those who have had a loved one cared for by the hospice. They can be referred to the service by a guardian, teacher or other health and social care professional known to them. Those aged 16 or over may refer themselves. The number of referrals made by schools for students with no prior link to our hospice continued to rise.

Community care

Our Community Specialist Palliative Care team provides specialist care and support to patients in their own homes, nursing and care homes. This care is currently delivered from 9 am – 5 pm, seven days a week and is available to patients living within Westminster.

The team work closely with patients, their loved ones and other professionals involved in their care such as a patient's GP, district nurse and hospital doctor to find the best plan of care. This will include managing pain and symptoms as well as providing emotional and practical support through home visits and telephone consultations. They will also refer to our in-house services such as social and welfare support, therapies, bereavement support, day services and inpatient care. In 2023, our Clinical Nurse Specialists made 1,609 home visits and 5,370 telephone consultations to a total of 205 community patients. The number of referrals continued to rise in 2023, and in Q4 referrals received increased by 60%.

For those living at home with advanced illness, deterioration in health can happen at any time of the day or night. Severe symptoms, sudden changes, or new problems may occur unexpectedly. Individuals and their carers – whether family or friends – may need to cope with all manner of crises and changes, large or small. People with life-limiting illnesses and their carers need seamless and high-quality specialist care so we are making it a priority to increase the service to cover 8 am – 8 pm, seven days a week, 365 days a year. We will also be improving our 24/7 advice line so that it is run by specialist palliative care nurses to ensure patients and carers can always contact a qualified nurse, meaning no individual or family is left to cope alone.



Day services

Our Day Care Unit in St John's Wood offers patients a creative and safe environment to access specialist nursing and medical care, benefit from treatments and therapies, meet with other members of our team such as our social workers and take part in workshops and activities. It is also an opportunity for them to meet other people who are living with life-limiting illnesses, have lunch and share experiences. The unit currently caters to people living within Brent, Camden and Westminster.



In May 2023, the unit closed, and services moved to a temporary on-site location while the construction of the new St John's Hospice Wellbeing Centre occurred. Due to the restricted space of the temporary site, numbers were limited to 11 patients per day. As such, priority was given to patients who were less well and/or struggling emotionally or mentally and would therefore benefit from the social aspect of the day services. Patients who would have otherwise come to the unit multiple times a week were scaled back to ensure all patients were still able to access services. Referrals to the service were limited to those most in need and was done in collaboration with our patients. More telephone consultations were made during this period to ensure regular contact with patients, particularly those who were coming in less frequently. Despite being in a smaller temporary space for over half the year, a total of 1,564 visits were made by 67 patients.



“The hospice is such a bright place to be, full of love and the most wonderful people. Without the Day Care Unit, I would just be sat home all day and that would be very boring but also extremely lonely.”

– Juan, patient.

Due to the restricted space, no new activities were introduced while in the temporary unit, however, poetry and reading group classes continued in smaller groups and outside in the seated area in the spring/summer and art classes continued virtually.

The Day Care Unit which reopened as the St John's Hospice Wellbeing Centre in January 2024 was generously funded by our donors. The new centre will cater for more patients and a broader range of conditions, as well as offer more outpatient clinics, therapy sessions and group classes including those for carers, recently bereaved and children's groups.

Hospice@Home

Our Hospice@Home service provides specialist palliative care at home so patients can remain in familiar and comforting surroundings in the last stages of their illness if that is their preference. As well as providing end-of-life care, the team also go into homes for assessments, to give patient's families and carers respite, and to help avoid unwanted emergency hospital admissions.

“Our Healthcare Assistant cared for my mother and supported us as a family tremendously in her last hours. She was very experienced and could identify the various stages my mother was going through. This meant that we were able to spend her last moments with her, as a family, just as she had wanted.” – Daughter of a patient.

Depending on a patient's needs, Hospice@Home care can be provided from a minimum of four hours per day through to 24-hour care, primarily in two-week blocks. In 2023, we provided 21,193 hours of care to 116 patients. This slightly lower number of patients, yet sharp increase in the hours of care provided is due to referrals being received in a timelier manner than in 2022, due to the COVID-19 pandemic. This model of care is preferable for patients, families and the team as it means trust can be established strengthening communication, understanding and empathy, a better experience for everyone.

Following 25 years of service one of our Hospice@Home Co-ordinators retired in November 2023. This position is now being recruited on a four rather than three-day-a-week basis to help support the increased caseload of the team. The capacity of the team has increased from last year through the recruitment of two additional Healthcare Assistants.

Inpatient care

At our Inpatient Unit, we support patients to get symptoms under control, and provide rehabilitation or respite care to support them and their carers so they can continue to live as independently as possible. Many of our patients are admitted for just a short while and are then discharged back home under the care of our Community Team. We also provide end-of-life care for patients who are in the advanced stage of their illness. This care is provided to patients living within Westminster, Brent, Camden, Islington, Hammersmith & Fulham, and Kensington & Chelsea.

A total of 235 patients benefitted from our inpatient care across 3,651 nights in 2023. We experienced a very slow start to the year which we believe was caused by delayed referrals and transfers of care because of doctor's strikes, a backlog in the NHS system and the increased



“You will never understand how blessed we felt being in this hospice and it being where our Mum was in her final days. You are so much more than clinical care. The word my Mum used a lot for your staff was kind. Kindness meant a lot to her, and we saw it for ourselves when we stayed there for 5 nights.” - Daughter of a patient.

preference of at-home care. Yet, in the last quarter of the year, we experienced a sharp increase in patient load and the unit was running at full capacity with a waitlist which can be attributed to the continued closure of the Pembridge Unit and the temporary closure of Marie Curie Hospice in Hampstead.

Delays in referrals from acute trusts and subsequent transfer of care, unfortunately, meant that end-of-life patients were reaching us within days of death, therefore limiting the holistic support we could give to patients and their families. Due to the continued pressure of a waitlist of end-of-life patients, it was, at times, necessary to delay admissions for respite patients.

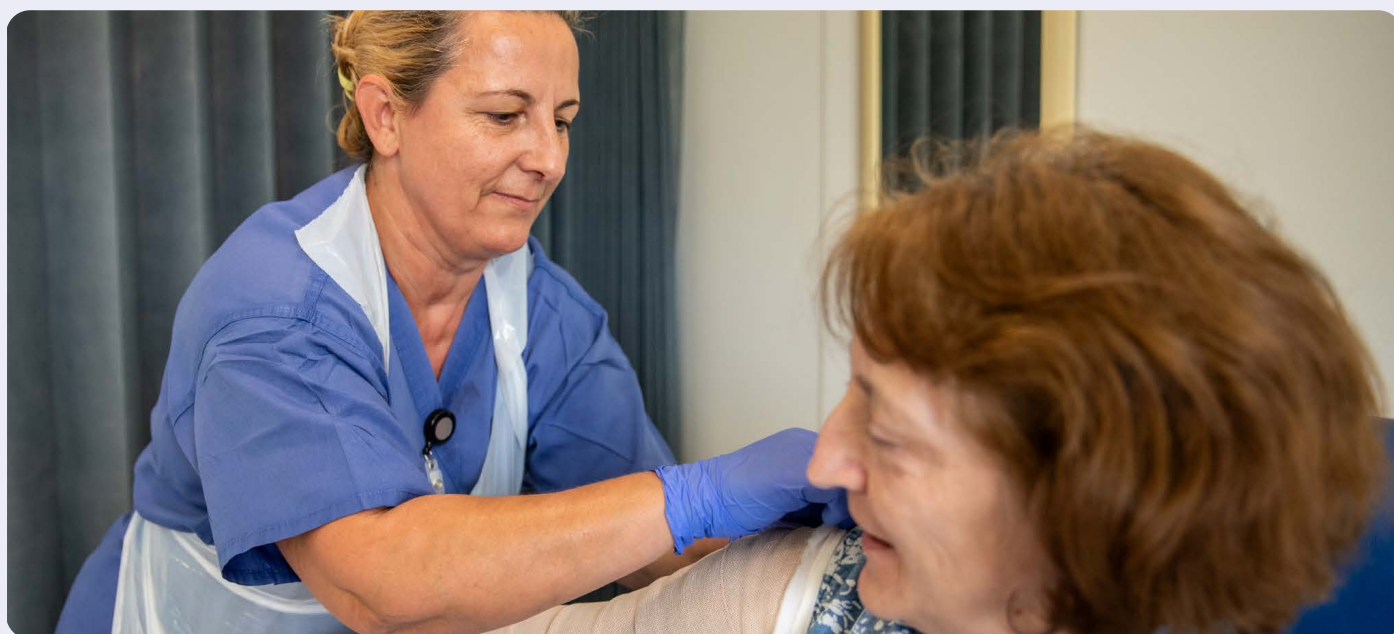
We successfully recruited a replacement Inpatient Ward Manager in February 2023 following the recruitment of a further Palliative Care Consultant at the end of 2022. This was to support the extension of our admissions to 8 am – 6 pm during weekdays. Extending our admissions over the weekend continues to be a priority for 2024.

Lymphoedema care

Our Lymphoedema care is available to patients living within Brent, Camden, Harrow, Hammersmith & Fulham, Kensington & Chelsea, and Westminster, where we are the only free provider of this specialist treatment.

Our Lymphoedema practitioners help patients to regain their quality of life, improve mobility and ease discomfort caused by the condition. They can also provide information and advice to educate patients on managing the condition. This care is provided at our hospice in St John's Wood and Charing Cross Hospital. Last year, 645 patients were supported across the two sites.

Referrals for our services continue to increase year on year. This is due to a lack of NHS services for patients living with non-cancer related Lymphoedema and those who have been living with the condition for more than two years. There has also been an increase in the number of patients living with Lymphoedema because of delayed cancer diagnosis and treatments during the COVID-19 pandemic. In the last quarter of 2023, we successfully secured funding to purchase some of the new equipment needed for our onsite clinic room in St John's Wood. The new equipment will improve the efficiency of the service in turn increasing the number of patients we can treat, helping to clear some of the current waitlist.



Social and welfare support

We recognise the impact that living with a life-limiting illness can have on our patients and their loved ones. Our team of social workers are here to help with any of the anxieties or concerns that they may have, supporting them by giving information and advice to ensure those needs are met. This support is provided online, over the phone, at our hospice or by home visits for patients living within Westminster.



Support includes providing emotional and practical support, such as giving advice on Lasting Power of Attorney, Will writing and funeral planning, as well as signposting to relevant external agencies if further assistance is required. They also advocate on our patients' behalf with financial and housing matters, department of education and social services.



The number of hardship grants issued almost doubled in 2023 in line with the rising cost of living. These grants have covered heating and energy bills, taxi journeys for hospital and outpatient appointments, essential appliances, furniture and short-term financial aid to support those with no recourse to public funding.

As mentioned earlier in the report, the team's capacity was increased in 2023 as the newly recruited Team Lead began in January and our part-time Social Worker increased her hours to four days a week. Later in the year, a part-time Administrator was also recruited to further assist with the team's increased caseload. The increased capacity of the team has meant that we were able to launch new initiatives such as a monthly group for carers and in early 2024, free workshops in partnership with funeral directors and solicitors on planning for funerals and Will writing will commence.

In Q4, thanks to the support of a donor, we were able to begin recruitment for the two planned additions to the team. The Welfare and Benefits Officer and a Clinical Psychologist will enable us to further expand our team's expertise and the number of patients we can support. We envisage both roles being recruited and in position at the start of 2024.

“Even though we live in the area I had never heard about St John’s before, so, having my nurse make that connection to such local services has been a great help. My social worker has helped with accessing additional financial support, providing information and advice on immigration and just helping us to adjust to our new normal.” – Radia, patient.

Therapies

Our physio- and occupational therapists help patients maintain or rebuild their strength and independence as well as supporting their physical needs and mental health and overall wellbeing. They visit patients at home, on the Inpatient Unit or at our day services. Patients are referred to these services internally through our community, inpatient and day care teams.

Unfortunately, the planned expansion of the services for 2023 took longer than anticipated due to difficulty in recruitment. Recruitment of the Team Lead and full-time Occupational Therapist was successfully completed at the end of 2023 and will be in position by early 2024. Recruitment for the remaining two positions of a part-time Physiotherapist and full-time Occupational Therapist will continue into 2024.

Complementary therapies

We deliver a range of complementary therapies including massage, reiki, reflexology and acupuncture at our Inpatient and Day Care Unit. Complementary therapies can work together with medical and nursing care to improve our patient's overall wellbeing, reduce anxiety, stress and fatigue, relieve some of their symptoms and aid mobility. These therapies are also extended to our patient's family members and carers.

In 2023, 1,728 complementary therapy sessions were provided for patients, family carers and bereaved loved ones at the hospice. We hope to increase our provision of complementary therapies at the hospice and to launch the service in patients' homes by increasing the contracts of all current therapists and recruiting two additional posts.

“The therapies are out of this world. I started off with acupuncture, and then I moved on to having massages on my legs and feet which I have found to be a great help. You can just switch off from the world, be alone with your thoughts, or chat with the therapist about what's on your mind.” – Christine, patient.



Our hospice priorities 2024 - 2028

Our fundraising and clinical teams have worked in collaboration to form the following priorities for the next five years. Working together in this way ensures that all our plans and priorities are firmly aligned.

The following 8 priorities span the work of the hospice as a whole and will be instrumental in transforming the way we help people living with life-limiting illnesses and their loved ones across North Central and North West London.

Priority 1: Extension of Inpatient Unit Admissions

We plan to introduce a higher level of medical and administration support to cover Saturday and Sunday ensuring we can safely accept new patients as well as look after current patients during the weekend. To do this, we will need to recruit an additional Palliative Care Doctor and a Weekend Receptionist.

Priority 2: Increased Community Nursing Provision

The NHS is introducing increased care levels in the community which will see an increase of cover for our community nurses to 8 am - 8 pm, 7 days a week, 365 days a year. We also want to improve our 24/7 advice line to ensure patients and carers can always contact a qualified nurse. To achieve this, we will need to recruit additional posts within the team.

Priority 3: Increased Complementary Therapies

We plan to reach more vulnerable patients in their homes and at the hospice with increased provision of our complementary therapies, assisting with pain management and anxiety relief. To achieve this, we will increase the contracts of all current therapists and recruit two additional posts.

Priority 4: Child Bereavement Expansion

Currently, St John's Hospice is the only provider in Westminster with a specialist service for children suffering bereavement. In response to the growing need for our services outside of Westminster, we plan to further enhance our current Social Work and Bereavement team.

Priority 5: Hospice@Home Expansion

Currently, there are boroughs within our catchment area with no Hospice@Home provision meaning patients with palliative care needs and their carers, are not able to access much-needed help at home. To expand the service into a borough with no current provision we will need to recruit additional staff.

Priority 6: Community outreach expansion

In order to expand our community outreach we plan to create a new community hub in another borough within our catchment area. The hub would offer clinics, social work and bereavement support, therapies and support groups. To achieve this, we will need to fundraise for the creation of the new hub as well as one year of running costs.

Priority 7: Updated patient vehicle fleet

It is vital to keep our patient vehicle fleet up to date and in good working order due to the dependence of some patients on the ambulance service. To achieve this, we must replace our current palliative care ambulance and passenger vehicle.

Priority 8: Creation of Education Hub

We plan to create a means of sharing our expertise with our staff and others in our sector to raise the quality of end-of-life care elsewhere in the health and social care system. We would like to offer workshops throughout the year in a blended learning approach ranging from introducing palliative care, through to symptom control, and on to considering ethics. Courses could combine independent learning with an instructor-led training element.



St John's Hospice

St John & St Elizabeth Hospital

Enabling people to live well for as long as possible





St John's Hospice is committed to celebrating and amplifying life, enabling people to live well for as long as possible. We provide quality, holistic care to more than 4,000 people across North London every year.

It costs over £7 million to offer our care completely free of charge. To be able to do this we rely heavily on public fundraising. Learn more about our hospice and how you can support us by contacting **020 7806 4011** or fundraising@hje.org.uk.



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