



The Louis Dundas Centre

Excellence in research,
practice and education

February 2022



**GREAT
ORMOND
STREET
HOSPITAL
CHARITY**



The Louis Dundas Centre was set up by Ruth Kennedy and Bruce Dundas as a memorial to their son Louis and in recognition of the desperate need to share knowledge of paediatric palliative care within the UK and worldwide.

Since its inception, the Centre has grown to not only deliver the highest standard of care and models of best practice but is playing a vital role in the development of an evidence base for children's palliative care research through publication, education and training.

The Covid-19 pandemic has been a particularly challenging time but the Louis Dundas Centre team have adapted to the changing environment to ensure that children and families can continue to receive the care and support they need. At the start of a new year, we would like to take this opportunity to highlight some of the Centre's recent achievements and share our exciting plans for the future.

The incredible achievements of the Louis Dundas Centre would not have been possible without your support. Thank you, on behalf of all the children and families that have been directly impacted by the work of the Louis Dundas Centre.

THE LOUIS DUNDAS CENTRE: HISTORY AND VISION

The mission of the Louis Dundas Centre is to make a tangible difference to the lives of children with life limiting conditions or life-threatening conditions and to the lives of their families.

Ruth and Bruce's vision to improve palliative care services for children came at a critical juncture in the development of palliative care services for children and young people in the UK more widely. A number of elements came together, providing an opportunity to create something potentially transformative for children's palliative care.

In 2008, the UK government launched *Better Care Better Lives*, a national strategy for children's palliative care backed with a pledge of £30 million to improve services. During the same period, the Association of Children's Palliative Care Trust (now *Together For Short Lives*) began advocating for change. Around the same time, The True Colour's Trust, one of the grant-making trusts of the Sainsbury family, had decided to create a professorial Chair in paediatric palliative care to provide leadership and gather momentum in the field.

After a competitive process, Great Ormond Street Hospital's (GOSH) dedicated research partner, the UCL Great Ormond Street Institute



for Child Health (ICH) was successful in securing this post and appointed Professor Myra Bluebond-Langner.

To capitalise on these important developments, Ruth and Bruce established the Louis Dundas Centre at GOSH/ICH - the UK's first integrated clinical academic centre for children's palliative care.

Over the last twelve years, your generous donations to the Centre have made possible the team's vital work, funding posts in the academic unit, the clinical team and the paediatric pain research group. While, in tandem, The True Colours Trust has supported the direct costs of the Chair of Paediatric Palliative Care offering strong leadership to the integrated academic unit.

SUPPORTING FAMILIES THROUGH THE PANDEMIC

When March 2020 saw the first Covid-19 lockdown affect England, the Louis Dundas Centre was quick to adapt to new ways of working to ensure minimum disruption to patient care and experience.

A locum palliative care consultant was appointed with the team also supporting partners during the pandemic (PMART UCLH and Royal Free Hospital). Despite the challenges of Covid-19, the team maintained activity and support with a 24-hour on-call service and home visits to 233 children.

Family virtual contact via phone and video almost doubled in comparison to the previous two years. While there was a 25% reduction in offsite visits in 2020/2021 due to restrictions, the same number of hours was spent with families.

KEY ACHIEVEMENTS

The Louis Dundas Centre is now a hub for international professional development. The Centre has provided training for UK registrars and doctors from overseas, some of whom have gone on to establish and lead on new tertiary palliative care teams in the UK or in their home countries.

As more children survive what were once fatal illnesses, the team at the Louis Dundas Centre is leading the way with more research focusing on the impact of a life-limiting illness and treatments on quality of life, and the overall experience of families. Here are some examples of these innovative research projects, and the impact they have had:

Groundbreaking advances in pain and symptom management

Together with colleagues in the school of pharmacy, the Centre has embarked on a multidimensional agenda to begin to fill some of the greatest and most significant gaps in paediatric palliative care pain and symptom management. Significant advances include:

- Improving our understanding of the efficacy of buccal morphine for pain relief in the management of pain symptoms in children with life limiting conditions.
- Understanding optimum delivery of methadone for pain relief.
- Better management of respiratory symptoms including breathlessness at the end of life.
- Relief of intractable nausea and vomiting.
- Better identification and management of incidences of breakthrough pain.
- Improved overall management of end-stage renal disease.
- Use of patient-controlled analgesia in the home for effective management of pain.
- Mitigating sources of medication error.

Insight into patient and family wishes

The Centre's research has shown that what adolescents want and what they hope to achieve in decision making about their care and treatment may not be what their clinicians or parents want. Studies of terminally ill adolescents and young people indicate that they do not want a solo voice. Like adults, they want to be able to

decide whether the decision is to be made by themselves or in consultation with others. The results of this research could lead to clinical guidance intended to aid clinicians in delivering empathetic care aligned with the goals of children and parents.

Key research also revealed insights into common misconceptions of families' wishes. Death at home is often held up as a marker of a "good death" and helping parents to achieve that is considered good practice. The team's research revealed that not only is there no evidence for such assertions, but they are also a misrepresentation of what parents and palliative care professionals support. In their clinical practice, the team now approach discussions with parents about their preferences with consideration and appreciation of what would work for that family. They are also looking at ways to better support a full range of options for place of care and place of death, including the development of a "Flying Squad" for rapid discharge from hospital to home or hospice.

The relationship between parents and clinicians is critical to the care of terminally ill children. A breakdown in the relationship can have lasting consequences for both families and clinicians. The team have defined key factors that affect the success of consultations and parent-clinician relationship. Their findings have now been incorporated into medical and nursing education and training both within paediatric palliative care and across paediatric specialities where seriously ill children are seen (e.g., oncology, cardiology, intensive care).

Timely referral and engagement

Timely referral to paediatric palliative care services is essential for the delivery of optimal care for the child and family. An NHS England initiative in adult cancer services aimed to improve early referral by implementing a framework of enhanced supportive care (ESC) that provided clinicians with a shared, specific vocabulary to support early referral. The team at the Louis Dundas Centre trialled this initiative with children. As a result, an agreed definition of "poor prognosis"

was developed in discussions between palliative care and cancer specialists, which allowed the majority (75%) of children in the pilot to be offered an ESC referral within one week.

Early engagement in advance care planning is seen as fundamental for ensuring the highest standard of care for children and young people with a life-limiting condition. It is also widely supported by policymakers and institutions, but parents are often resistant to engaging in these discussions. The research team recommended that clinicians have regular discussions over the course of the illness to understand parents' approaches and allow them to keep their options open, rather than to drive them to specific decision or to closure prematurely. Having the results immediately and directly from the academic researchers, the clinical team were able to

alter practice and incorporate the findings into education and training including the simulation course on end-of-life care.

These achievements would not have been possible without the efforts of the talented Louis Dundas Centre team pictured below.



SUCCESS IN NUMBERS

Since the Louis Dundas Centre's inception, the team have achieved various successes including:

- **126** Leadership positions on national and international initiatives in Paediatric Palliative Care
- **16** Editorial positions (including editorships and membership on advisory and editorial boards of peer reviewed journals)
- **11** Invitations to collaborate on proposals for research funds with institutions external to the LDC.
- **236** invited lectures, presentations, plenary talks, keynote addresses and workshops at professional meeting and conferences
- **99** articles published in peer reviewed journals (9 available online first, 62 available in print)
- **24** chapters in textbooks; including 6 chapters in the award winning sentinel textbook: Goldman et al Oxford Textbook in Paediatric Palliative care (2012)

EXTERNAL EVALUATION

An external evaluation of the Louis Dundas Centre in 2016 by the Care Quality Commission rated the end of life care provision within the clinical unit as 'outstanding'. The team were thought of highly by colleagues within the hospital and by other professionals from around the world.

The Louis Dundas Centre academic programme also underwent an external review in December 2018 and the work of the centre was highly commended by an external academic panel. The panel commended the tenacity of Ruth Kennedy for spearheading the vision and raising funds as well as the leadership of Lucy Sainsbury and the True Colours Trust in establishing the first paediatric palliative care Professorship in the world.

"The External Review Board commend the funders on their vision and leadership in the field to boost paediatric palliative care, generous support for the chair and the programme. They are commended for collaborating effectively. This approach is a good model for future funding initiatives, nationally and internationally and should be celebrated and promoted."

AN UPDATE FROM DR SUELLEN WALKER

Pain is one of the most concerning symptoms of disease or therapy for children, and it causes distress for patients and their families. Chronic pain has a significant impact on physical function and emotional well-being in children.

The Louis Dundas Centre has provided continued support to the Paediatric Pain Research Group at UCL GOS Institute of Child Health (ICH), and has made significant contributions to its development. Both clinical research and translational laboratory projects have seen a significant improvement in productivity as a result.

Here, Dr Suellen Walker, Pain Management Honorary Consultant in Paediatric Anaesthesia and Pain Medicine shares more on the group's positive progress.

Pain Management

We see around 2,000 children in the hospital each year who require specialist management of pain following surgery, cancer treatments or associated with different medical conditions. Chemotherapy has increased survival for many children with cancer, but it is also linked to mucositis, which is caused by harm to cells in the mouth and gastrointestinal tract. This can be associated with severe pain for weeks that requires intravenous opioid analgesia. We keep a database of children managed by the pain service, and conducted an audit of seven years of our practice. This highlighted that the doses and duration of opioids vary significantly with time and between individual patients, and the important need for members of the Pain Service to review these patients each day, and adjust the analgesia according to each individual patient's need. We combined this with a systematic review of the literature which confirmed that our experience and practice at GOSH is comparable with other centres. This work is now published and provides valuable data for teaching and training, as well as informing discussions with families about how we manage this difficult pain condition.



Diagnosing neuropathic pain

I also see patients in our chronic pain clinic, many of whom have severe nerve-injury or neuropathic pain related to different types of injury or disease, or rare genetic disorders. This type of pain can be difficult to recognise and manage. Quantitative sensory testing (QST), neuroimaging, and questionnaires have been used to assess the impact of neuropathic pain, discover the mechanisms causing this form of pain, and, ultimately, establish which type of medication is most beneficial for individual patients. LDC funding has been essential for buying the necessary equipment and establishing our sensory testing room in the hospital.

New collaborations

We're working with Dr Vesna Pavasovic and staff in the Late Effects Clinic to assess pain and sensory function in childhood survivors of haematological cancers. Long-term persistent pain that may be related to prior chemotherapy and cancer treatments are increasingly identified, and a proportion of these children experience fatigue, sensory changes, and pain that can have a negative impact on their quality of life. Identifying these changes will highlight the need for assessment of pain, and referral for management, as part of routine evaluation of late effects. Our team has become part of the Advanced Pain Discovery Platform (APDP), which is a £24 million initiative funded through the government and delivered by the Medical Research Council, ESRC, BBSRC, Versus Arthritis and Eli Lilly. It's a fantastic initiative to be part of and it has been a huge push to increase both collaborative working and pain awareness and funding throughout the UK.

Consortium Against Pain inEquality (CAPE)

We are involved with the APDP-funded Consortium Against Pain inEquality (CAPE), and this has provided further funding for Dr Madeleine Verriotis, who has now completed her 5-year term as a senior post-doctoral researcher, to continue working with the Paediatric Pain Research Group. The Consortium looks at the impact of early life experience on adult pain. We have always been interested in what impact pain would have on the future development of children and their pain experience, as well as looking at children who are in pain now. So, even though much of the work happening through the Consortium will be through assessing adults, it is critical that we're involved to provide some perspective on what occurred to them as children and how it may have related to suffering later in life.

Juvenile Idiopathic Arthritis

Madeleine will also be working with the Adolescent and Young Adult Rheumatology clinic at UCLH (University College of London Hospitals) to evaluate pain in young adults (18-24 years) with juvenile idiopathic arthritis. Madeleine will be using techniques she has learnt during her time funded by the LDC (quantitative sensory testing and neuroimaging), in addition to several questionnaires related to physical function and emotional well-being. We hope to assess factors associated with either risk of increased pain and pain-related disability, or resilience and reduced pain. This will help identify points for intervention and management.

Recent publications

The Lancet recently commissioned a major article about paediatric pain with contributions from an international panel of authors (including members of the LDC PPRG) and patient partners. This identified four objectives:

Make Pain Matter (to health care professionals, policymakers, funders, researchers, and the general public)

Make Pain Visible (standardised assessments with a person-centred approach)

Make Pain Understood (mechanisms incorporating biological, psychological, and social factors);

Make Pain Better (avoid unnecessary pain and improve access to effective treatments).

Our PPRG research and teaching aligns with these goals. The Lancet document is also having a wider impact as the UK NIHR (National Institute for Health Research) has now released a Health Technology Assessment Commissioning Brief specifically for projects related to pain management for children and adolescents.

Looking ahead

The pandemic has had a significant impact on recruitment to our clinical research studies. Fortunately, we had collected most of our neuropathic pain study data prior to the pandemic and have been able to spend time analysing and writing up our results, and related review articles. This is also important as we were unable to continue clinical recruitment to our Late Effects Study, as many children were being reviewed by video appointments rather than attending the hospital. We are now seeking funding for staff to support ongoing recruitment, and hope to have sufficient numbers that we can compare some outcomes pre- and post-pandemic, as this has had effects on children's school, social and emotional function.

Our quantitative sensory testing laboratory has expanded from research to a clinical service for children with chronic pain, and is unique to GOSH. We are aiming to gain ongoing funding to further develop and staff this service, and demonstrate its benefit not only for children at GOSH, but also to provide evidence for use at additional centres.

LEADING THE WAY FOR A GLOBAL CHILD PALLIATIVE CARE PHARMACIST NETWORK



Bhumik Patel joined the Louis Dundas Centre in August 2017 as the UK's first paediatric palliative care pharmacist embedded within a tertiary paediatric palliative care team. The post was initially funded for three years in 2017, with Bhumik's time split 60/40 between research and clinical activity.

His role has been so successful that the Great Ormond Street Hospital now fully funds the post, and the job description has since been distributed to other palliative care teams across the country, as the importance and need for roles like Bhumik's becoming more widely recognised.

Bhumik says, "This has been a pioneering role in paediatric palliative care not only in the UK but also abroad. I am building a network of paediatric palliative care pharmacists across the world to provide support and evidence in this area so that we can develop and learn from shared excellence. Since I started here, an associate specialist working with the LDC team has returned to Melbourne and recruited a paediatric palliative care pharmacist to mirror our set up. Similarly, after seeing the way we worked, a paediatric palliative care pharmacist has been employed in the United Arab Emirates."

"Evidence based practice is a fundamental principle of safe and effective care. In paediatric palliative care many medications have been used historically to manage symptoms, but with limited evidence to establish the true effectiveness of medications. Much of my work since starting has been shifting that dynamic to try to develop the evidence base and help ensure the prescribers are following the evidence-based recommendations, improving outcomes."

The aim is to try and develop a supportive research network in the same way that adult palliative care pharmacists have done for a number of years, with a dedicated research links with established consultant pharmacists who present at international and national forums and conferences to share information.

"Pharmacy research in palliative care for children needs to catch up with what is already established for adults. We need to develop a supportive research network in the same way that adult palliative care pharmacists did 30 years ago. Paediatrics needs to start small and spread so that as it becomes more publicly recognised, there is a pharmacist network on the ground."

Bhumik's work on *aprepitant*, a new drug used to treat nausea and vomiting, was published in February 2021. Bhumik presented an oral presentation on *aprepitant* and a poster on *levetiracetam*, an anti-convulsant, at the 10th European Association for Palliative Care conference in October 2019. Bhumik says, "We were the first paediatric group to use *levetiracetam* in the treatment of end-of-life seizures. Despite it only being presented as a poster, after the conference Professor Bluebond-Langer was approached by Elsevier to discuss our work, and an article was published in *Practice Update*, an online portal for healthcare professionals.

Bhumik has worked with and continues to work collaboratively with UCL (University College London) school of pharmacy, to look at how drugs are administered to patients. His team are looking at whether methadone could be made into a buccal or transdermal (via cheek or skin) formulations. They have proved the concept and are in the process of evaluating how to translate this research into the clinic and beyond. Another stream of research is looking at the patient experience once away from hospital. One important aspect of this study is checking the availability of medication at home. The research going forward will have an impact on how 'at home care' is perceived in the future and what can be done to ensure that the standards are high at both home and hospital settings.

Bhumik has been awarded prizes by the European Association of Palliative Care and is now a registered prescriber. He looks forward to taking his research streams forward in the next 5-10 years as well as further advancing and improving care delivery and governance in the delivery of end-of-life care for children.

LOOKING AHEAD TO THE FUTURE

The Louis Dundas Centre continues to forge ahead whilst building national and international collaborations and investing in important educational programmes to support the high-quality care so greatly needed by young patients and their families.

One of the original aims when establishing the Centre was to serve the long-term sustainability of the clinical palliative care service when charitable funding came to an end in 2020. Following the success of the clinical team, and in recognition of the important role they play across all departments of the hospital, a commitment has been made to the long-term funding of the service.

In December 2021, Professor Myra Bluebond-Langner retired as the Chair of Paediatric Palliative Care marking an end to a significant tenure. As we look to the future, the Centre will build on Myra's leadership as we appoint an outstanding new candidate in 2022.

The new Professor of Palliative Care Chair will be funded in part through an endowment fund made possible from the generous donations you have made to the Louis Dundas Centre.

Over the coming year the team have extensive plans to develop their service. They will be collaborating with specialist care palliative teams across the UK to develop a rapid response Flying Squad model for children and their families who wish to be quickly discharged from the hospital and sent home safely. To improve family experience, they will be recruiting a dedicated palliative care play specialist as well as a Specialist Nurse in partnership with Haven House Hospice.

There are also plans to scope out transforming specific spaces within the hospital to respond to the feedback and needs of the families under the care of the palliative care team, such as exploring a multi-purpose end-of-life room on the cancer ward, so that families have a space that is comforting and private in these important moments.

Finally, the team at the Louis Dundas Centre hope to share their expert knowledge and research for the benefit of care teams and families across the hospital and elsewhere in the UK, by making the Paediatric Palliative Care Foundation course available through GOSH Learning Academy, GOSH's digital learning platform.



Professor Myra Bluebond-Langner

“Over the last 12 years, we have developed and refined cutting-edge methods to better understand what parents and clinicians want and need as they care for a seriously ill child. We have provided clinicians with robust evidence to improve practice and to reduce suffering. We would not have been able to develop our approach without your generous support. And we certainly would not be able to make the discoveries and innovations described in this report. Your support for the Louis Dundas Centre has secured a firm foundation for continuing discoveries and innovations for the benefit of seriously ill children and their families.”



“There is such heroism in this field, It’s not heroism associated with cure, but with looking after people at their absolutely most vulnerable. I’m immensely proud of what they do.

But, there is still so much to be done.”

Ruth Kennedy

On behalf of our patients, families and the palliative care team at the Louis Dundas Centre, thank you for all your wonderful support.

THANK YOU!