

**GREAT ORMOND STREET
HOSPITAL FOR CHILDREN**

Welcome

**LOUIS DUNDAS CENTRE FOR
CHILDREN'S PALLIATIVE CARE**

IMPACT REPORT

**MAKING A DIFFERENCE IN CHILDREN'S
PALLIATIVE CARE RESEARCH PRACTICE
AND EDUCATION**

**ON THE 11TH ANNIVERSARY OF OUR
FOUNDING**

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INSTITUTE OF CHILD HEALTH

The Louis Dundas Centre [LDC] 10 Years On:
A Centre of Excellence in Research, Practice and Education

Introduction

Paediatric palliative care [PPC] aims to reduce the suffering of children with life-limiting and life-threatening illnesses and their families. This endeavour requires an evidence-based clinical practice built upon a cross-disciplinary understanding of seriously ill children and their families - their experiences over the course of the illness, the decisions they make and how they make them^{1,2,3,4,5,6,7}.

The LDC was created to make such paediatric palliative care a reality by, in a bold move, creating a multidisciplinary academic research unit paired with an established expert clinical paediatric palliative care team. Together the members of the LDC have pursued an integrated program of research, practice, education, and training in order to develop and disseminate this needed understanding of seriously ill children and their families. Using this unique and pioneering model the LDC has had a major impact not only on the lives of the children and their families, but also on the field of paediatric palliative care - a new and developing field where the practice had outpaced research (See Appendix - Mission and Vision Statements). This innovative model has now been adopted and adapted by other academic institutions and palliative care teams throughout the UK.

The LDC has been the leader in the UK in moving the field from eminence based to evidence-based research and practice. Its contributions to the field go well beyond its borders (See Appendix - Snapshot of Progress Reported Against Vision). Below are 10 thumbnail sketches outlining some of the contributions our integrated model has made both to the field of PPC and in the lives of seriously ill children and their families.

Ten Seminal Contributions of the LDC to Research, Education and Clinical Practice in Palliative Care for Children and Young People

1. When we fail to ameliorate a child's physical suffering we fail that child, family and ourselves. Together with our colleagues in the school of pharmacy, the LDC 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^{8,9,10,11}. Our work has led to seminal breakthroughs in our understanding of the efficacy of buccal morphine for relief of pain¹², optimum delivery of methadone for pain relief^{13,14}, management of breathlessness at the end of life¹⁵, relief of intractable nausea and vomiting¹⁶, as well as the incidence of breakthrough pain^{17,18}, overall management of end-stage renal disease¹⁹, use of patient-controlled analgesia²⁰ in the home for more effective management of pain, and sources of medication error^{21,22}.

Because of the Centre's model of integrated working - research, clinical practice and education- the clinical team was able to bring these discoveries and new information immediately into their practice as well as to the larger paediatric palliative care

community through its training and commentaries in *Association for Paediatric Palliative Medicine Formulary* – medications guide used by practitioners.

Over the next year, we will continue to explore ever more effective approaches to pain relief including the use of methadone for effective pain relief^{13,14}, over encapsulation²³ of oral medications so that child can take a number at once as well as access and supply of medications critical to the relief of pain and difficult to manage symptoms when a child's condition is deteriorating and death is nigh.

2. Timely referral to paediatric palliative care services is essential for the delivery of optimal care for the child and family. Late referral deprives children and families of the enhanced symptom management and assistance in decision making which a palliative care team provides. It makes establishing the presence which PPC might have had, more difficult or even impossible to establish. But one hears all too often from clinicians and parents "Why wasn't this child referred to palliative care earlier?"

The LDC academic unit has both uncovered barriers to referral and developed innovations to reduce barriers^{24,25,26,27}. Our very first educational initiative across 20 neonatal units in London demonstrated that a locally delivered, locally focused session on paediatric palliative could not only change attitudes and understanding, but also lay the groundwork for the development of systematic referral²⁸. This work led to the creation of a national lead nurse in neonatal nursing and with it to increased referral to palliative care with many neonatal teams and babies supported by the LDC palliative care team. Moving on from neonatal the next frontiers will be further back in the trajectory to the antenatal period working in tandem with specialists in foetal medicine, cardiology, and intensive care^{29,30}.

3. Death at home is often held up as a hallmark of a "good death" and helping parents to achieve that as a marker of good practice. Our research revealed that not only is there no evidence for such pronouncements, but they are also a misrepresentation of what parents and palliative care professionals support^{25,31,32,33}. The actual preferences of families are diverse and driven by social, economic, and personal factors. When such well-intended but fallacious slogans become widespread, they can have a negative impact on children and families with LLCs and LLIs. Parents may feel pressed or expected to make a choice which is not in the family's or child's best interests. One of the defining aims of palliative care is to reduce the harm, the suffering that we unintentionally create through unexamined policies and practices. In our academic publications, presentations and clinically led teaching we have corrected this unfounded assumption. In our clinical practice, we approach discussions with parents about their preferences in place of death not with an idealised notion of "good death equals death at home" but rather with consideration and appreciation of what would work for that family, conscious of available resources. Currently, we are 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.

4. The relationship between parents and clinicians is critical to the care of seriously ill children. A breakdown in the relationship can have lasting consequences for both families and clinicians. Through our research, we have identified key factors that bear on the success of consultations and the maintenance of the essential relationship between parents and clinicians as well as factors leading to a breakdown of the relation^{34,35,36,37}.

We have disseminated our results in major journals and at major conferences leading on to incorporation into medical and nursing education and training both within PPC and across paediatric specialities where seriously ill children are seen (e.g. oncology, cardiology, intensive care).

5. Advance care planning (Do Not Attempt Resuscitation Orders, Ambulance directives, plans and preferences in place of care and place of death) is widely endorsed by policymakers and institutions; however, parents are often resistant to engage in such discussions. The result is that parents are distressed by being confronted with issues which they find painful to discuss, and clinicians feel inadequate in the performance of their job.

Our research uncovered the bases for such resistance and proposed solutions based upon an approach to advance care planning not as the completion of an agenda but as the sensitive, individualised initiation of the exploration of painful but unavoidable issues^{38,39,40}

Because of our unique relationship with the clinical team, there was not the usual time lag between such discoveries and implementation in practice and education. Having the results immediately and directly from the academic researchers, not having to wait until publication (often a year or more between submission of an article and publication), the clinical team was able to alter practice and incorporate the findings into education and training including their well evaluated oversubscribed simulation course on end-of-life care.^{41,42}

6. Prognostic information about seriously ill children is challenging for clinicians to reveal and painful for parents to receive. Yet it is something that many argue is something parents must know in order to make informed decisions about their child's care, treatment and future. Yet many studies report clinicians failure to provide any or even adequate prognostic information. They report further that what information is given is poorly understood by parents. Our studies of the actual on the ground conversations between oncologists and parents of children with high-risk brain tumours (audio-recorded and transcribed verbatim) at diagnosis has revealed that an essential issue for parents is not the lack of information or poor information, but rather how to apply complex, often general and statistical information to their specific, unique situation³⁶. From the parents' point of view, the outcome will be 0 or 100. We are currently analysing consultations as the disease progresses and will, as is our practice, propose clinical guidance based on our findings. There are indications that our findings apply to clinicians and parents of children with other illnesses including complex cardiac condition; those in intensive care or

awaiting transplant. Part of the work of the PPC Team is helping the parents to understand prognostic conversations and their impact on decisions going forward.

7. As more children survive what were once fatal illnesses more research is focusing on to the impact of their illness and its treatment on their quality of life as survivors. PPC also stresses the importance of quality of life for children who will not survive their illness. However, what quality of life means to clinicians, children and parents and how it figures into their decisions has not been explored.

Beginning with a study of children with high-risk brain tumours we are looking at the different meanings that this critical element in decision making has for children, parents and clinician, and how the meaning of QoL changes over time. The results of this research will lead to clinical guidance intended to aid clinicians in delivering empathetic care aligned with the goals of children and parents^{36,37,43,44}.

8. Policy documents, clinical guidance and ethicists urge children's involvement and participation in decision making. This principle can be applied in ways which lead to conflict between clinicians and parents. Some parents may want to limit or filter the information which children are given about their illness and its prognosis. At the other extreme, some clinicians might want to make an adolescent the decision-maker.

Our research indicates that this may not accord both with what adolescents want and what they hope to achieve in decision making about their care and treatment^{45,46,47,48,49,50,51,52,53}. Studies of seriously ill adolescents and young people indicate that they do not want a solo voice. They, like adults, want to determine the information they receive about their condition, illness, care and treatment and perhaps delegate someone else to receive it. Again, like adults, they want to be able to decide whether the decision is to be made by themselves or in consultation with others.

The lack of alignment between international policies such as the UNCRC (United Nations Convention on the Rights of the Child) and the ways in which it is interpreted and put into practice guidance and ethics frameworks can be extremely challenging for clinicians. Clinicians report that drawing on research, citing evidence such as our work helps them in dealing with colleagues who may be using official guidance and policy in ways which they feel are not only inappropriate, but also potentially harmful.

9. Parents' and patients' participation in research is essential for building the evidence base and improving the care which children and families receive. While participation in research is and has been routine in several paediatric specialities this has not been the case in paediatric palliative care. We found that one of, if not the most significant barriers was clinician gatekeeping - passive as well as active resistance to inviting families onto research studies^{54,55,56,57}. Which such resistance is motivated by the honourable intention to protect families; it has the unfortunate consequence of small and biased research samples leading on to less than reliable results for guiding

practice and policy. Investigations of families' experience with research, however, shows that most parents and children welcome the opportunity to participate, and some report benefits from their participation.

Working as an integrated Centre we have been able to develop, implement and evaluate a number of approaches to increase invitation and access to research studies⁵⁸. This has led to increased parental and children's access and participation in research; something which parent and children want to do, and we have an obligation to provide. Continued work in parent public involvement and engagement in research will help to ensure the development of this most precious resource.

10. Known for the depth and breadth of our clinical practice as well as cutting edge, foundational research the LDC is a destination point for professional development^{26,59,60,61}. We have provided training for UK registrars and foreign doctors, some of whom have gone on to establish and lead on new tertiary palliative care teams in the UK or in their home countries.

The LDC has hosted clinical academics and established researchers from all over the world, on both short and extended study leaves. This had led to collaborative projects in communication and decision making in paediatric palliative care as well as models for research development and delivery of palliative care.

Of Note:

Insightful studies depend upon the development and application of cutting edge methods. Over the course of the last 10 years, we have developed and refined 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, to reduce suffering. The methodology which we have developed for research in communication and decision making has been deemed, in an external review by an international panel of experts the "gold standard" for future work in communication and decision making^{62,63}. Marron J.M. 2020 described the work as providing "a nuanced description of how prognosis is discussed in this population, filling what had been a conspicuous gap in the pediatric oncology literature."⁶⁴

The development of this approach was made possible in large measure by the core funding received from donors to the LDC. Without this funding, we would not have been able to develop this approach. And we certainly would not be able to make the discoveries and innovations described here.

In short, the funding we have received has secured a firm foundation for continuing discoveries and innovations for benefit of seriously ill children and their families.

LDC MISSION STATEMENT

The LDC works to make a tangible impact in the lives of children and young people with life threatening and life shortening conditions. It does so through interdisciplinary research contributing to both practice and policy globally. Research is disseminated through publication, multidisciplinary national and international education and training, as well as by working directly with teams providing both palliative and disease-directed care and treatment.

LDC VISION

1. To be a nationally and internationally recognised centre for research on children with LLC and LTI.
2. To be a respected source of knowledge and advice for clinicians, professional bodies and policymakers.
3. To be an effective agent in and for the PPC sector.

SNAPSHOT OF PROGRESS REPORTED AGAINST LDC VISION 2010-2021

1. Nationally and internationally recognised centre for research on children with LLC and LTI

- 92 articles published in peer-reviewed journals
- 24 chapters in textbooks; including 10 chapters in the award-winning sentinel textbook in PPC: Goldman et al *Oxford Textbook in Paediatric Palliative Care*; and the only two chapters on children and young people in the Oxford Textbook of Palliative Medicine (6th ed.)
- Edited first-ever Special Issue in *Palliative Medicine* dealing with Paediatric Palliative Care
- 236 invited lectures, presentations, plenary talks, keynote addresses and workshops at professional meeting and conferences
- £3,928,294 in core funding (True Colours Trust, GOSH CC)
- £5,627,999 in external project funding as PIs or Co-PIs (European Research Council, Australian Research Council, Horizon 2020, NIHR CLAHRC North Thames with Barts Health, The Health Foundation, The Children's House, Marie Curie Cancer Care and The Raisa Gorbachev Foundation, Samuel Sebba Charitable Trust, Nelsons UK, Olivia Hodson Cancer Fund, Rutgers University USA, Department of Health England)

2. Respected source of knowledge and advice for clinicians, professional bodies, and policymakers (2010 to present)

- 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
- LDC research referenced in NICE Guidance on Paediatric Palliative and End-Of-Life Care
- LDC members gave evidence to the All Party Parliamentary Group for Children Who Need Palliative Care and LDC research has been cited in reports generated by this group.
- 17 Education and Training courses, workshops and study days fully subscribed with participants from around the world

3. To be an effective agent in and for the paediatric palliative care sector

- 126 Leadership positions on national and international initiatives in Paediatric Palliative Care over the last 10 years
- Provided evidence for national study to change the way paediatric palliative care is funded

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