

GROWING TOGETHER

Patient centred strategies for the development of LTV care

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East of England
Paediatric Critical Care
Operational Delivery Network
Collaborative working to deliver high quality care to our children and their families

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Paediatric Critical Care
OPERATIONAL DELIVERY NETWORK


The Yorkshire and Humber
Paediatric Critical Care
Operational Delivery Network


Thames Valley and Wessex
PAEDIATRIC CRITICAL CARE
Operational Delivery Network

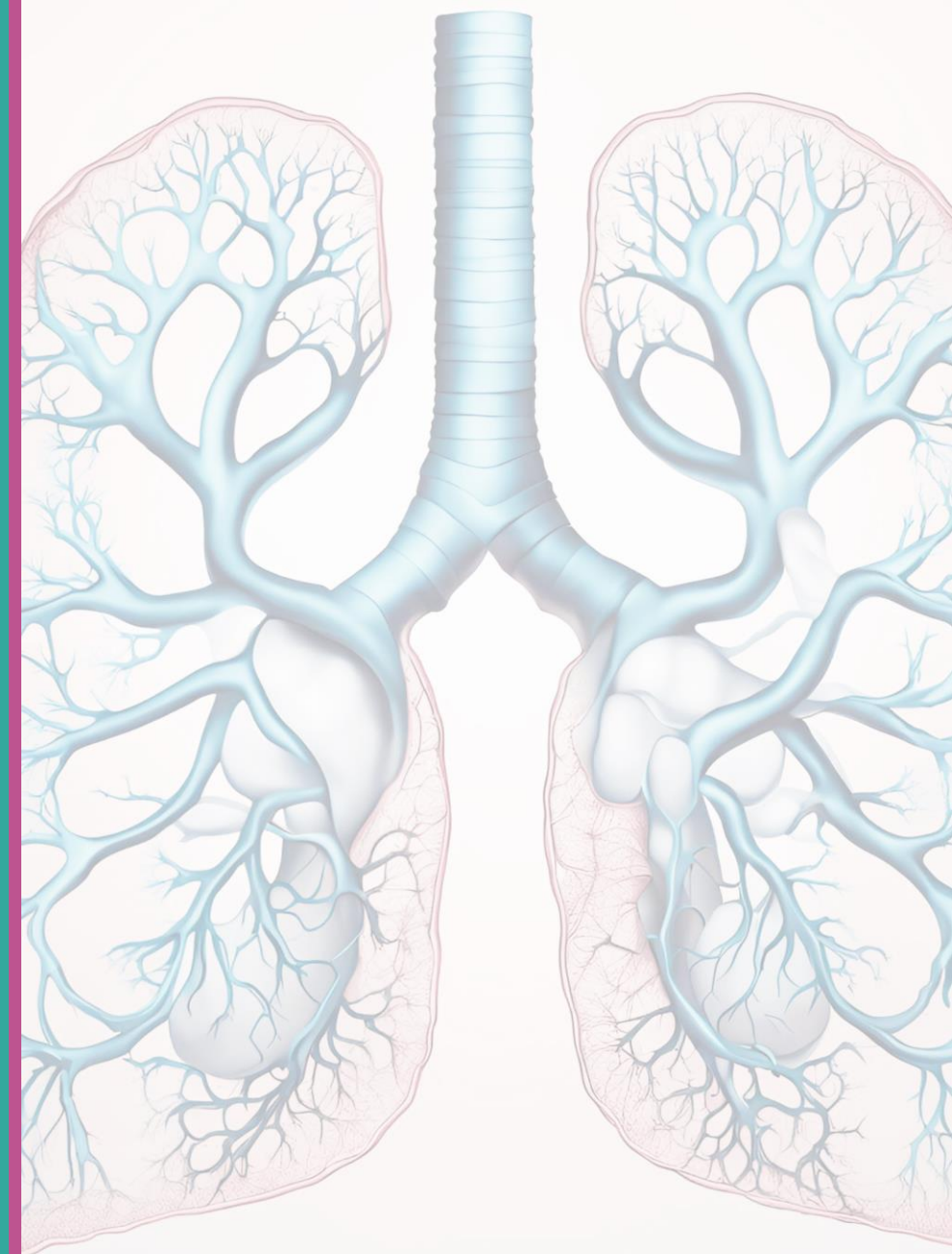
Pan Thames Paediatric LTV Programme

 North Thames Paediatric Network Connecting paediatric services	 South Thames Paediatric Network Transforming Healthcare for Children and Young People
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ODN SiC
LTV
NORTH WEST PCC




West Midlands
Children's Network

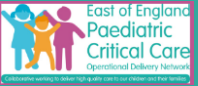


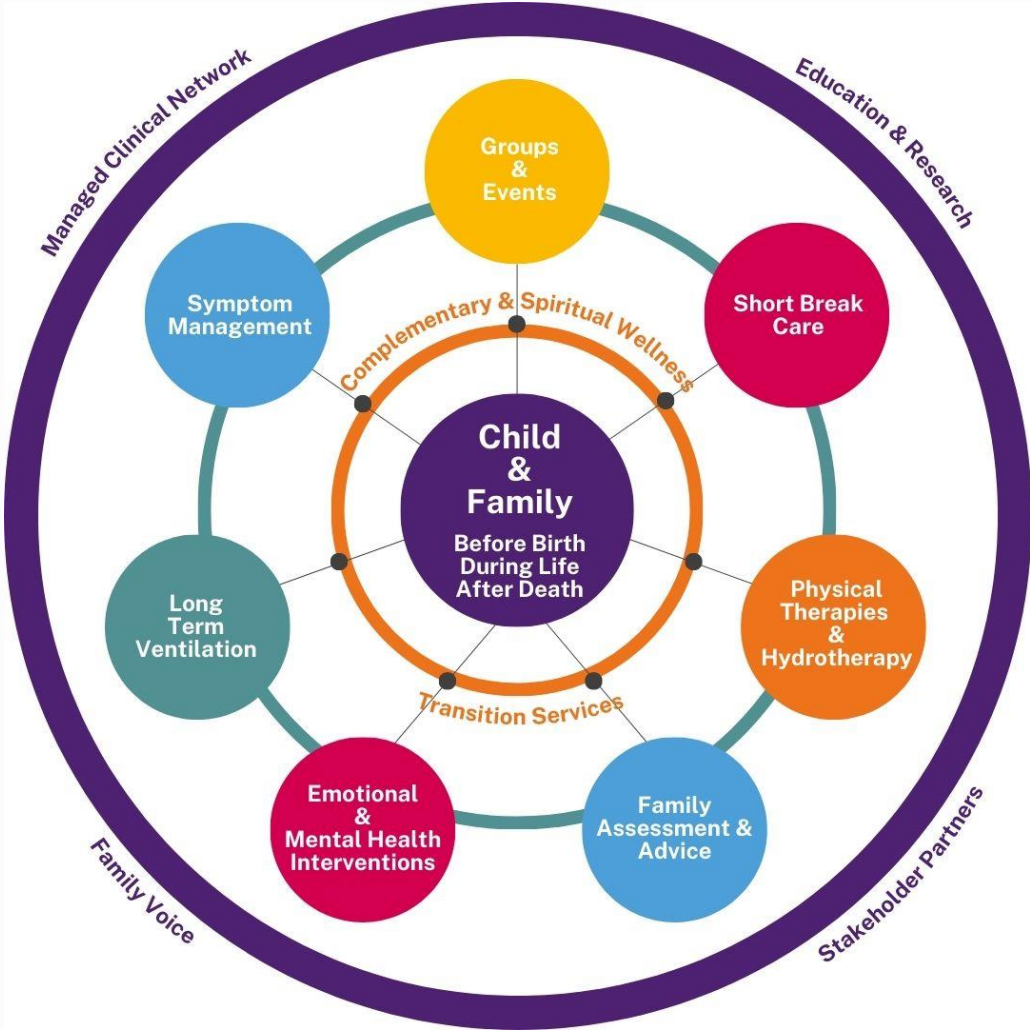
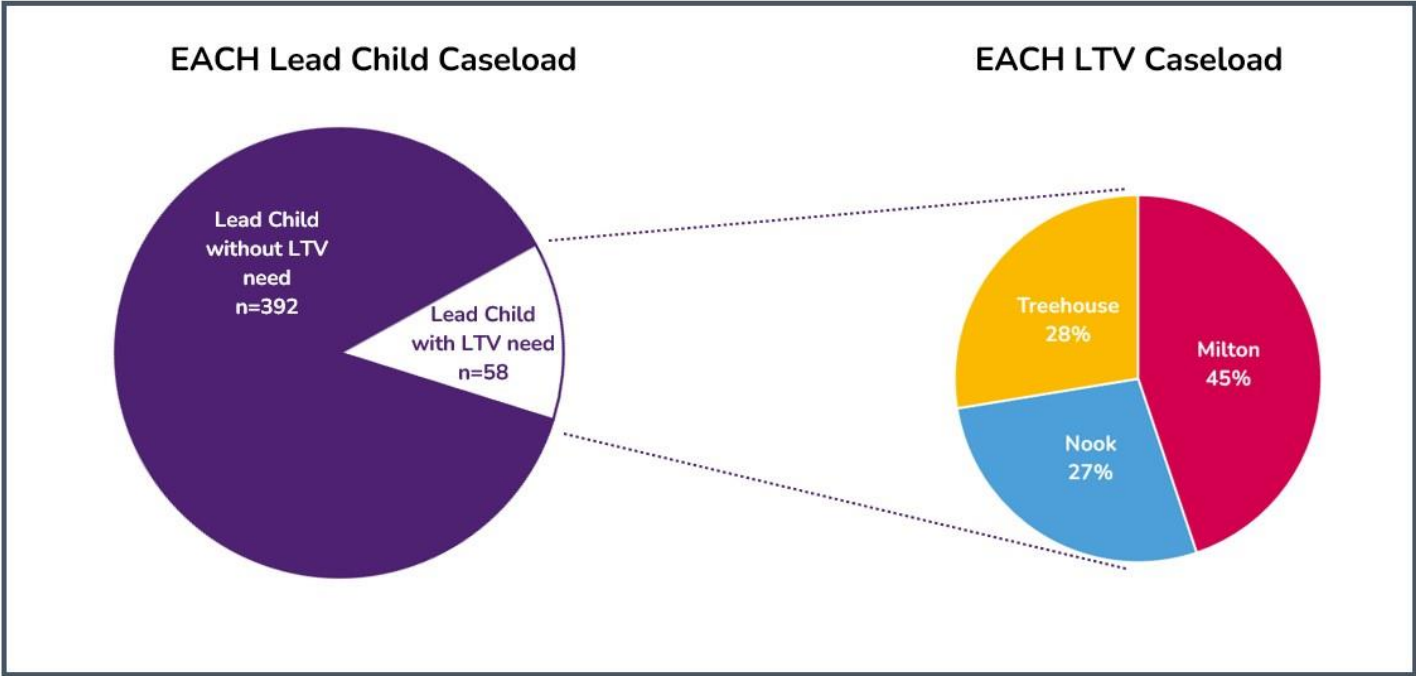
Long Term Ventilation at East Anglia's Children's Hospices

JENNA BENNETT - CLINICAL NURSE SPECIALIST LONG TERM VENTILATION & RESPIRATORY CARE

TINA DUFFIELD – ASSOCIATE PRACTITIONER FOR LONG TERM VENTILATION









Milton

Our hospice in Cambridgeshire



The Treehouse

Our hospice in Suffolk



The Nook

Our hospice in Norfolk

Making a referral to EACH

Ensuring the best possible quality of life, and making every moment count for children and families.

Let us help – make a referral to EACH - East Anglia's Children's Hospices



The LTV team at East Anglia's Children's Hospices

LTVS

Long Term
Ventilation Service





The EACH LTV Service

The LTV Service provides advice, support and hands-on care to EACH BCYP with a life-threatening condition or complex respiratory health need requiring long term ventilation or airway management support.



Specialist advice available Monday to Friday during office hours

Team Structure

The LTV Service, delivered by EACH, is comprised of a team of specialist nurses and associate practitioners. Recruitment has taken place this year for vacant positions.

1 Respiratory Clinical Nurse Specialists

LTV Nurses **3**

2 Associate Practitioners for LTV

Respiratory Care at EACH

- Supporting lead centres as an outreach to the local community
 - Planned medical reviews alongside acute teams
- Advocacy for BCYP and family
- Contribution as part of wider MDT and at multi-professional meetings
 - Specialist care in the community and within the hospice
- Training for EACH staff
- External LTV training and commissioned care



Jenna Bennett: Clinical Nurse Specialist LTV & Respiratory Care



- Began career in London, mainly working in gastro-surgical until I travelled to Australia and worked there for a short period.
- On my return, I joined PICU at CUH, where I worked clinically, undertaking HDU and PICU courses. Involved in multiple end of life's- PICU based.
- I then split my hours between clinical shifts and hours working for the NIHR as a research nurse for PICU.
- Alongside this, I honed my home ventilation skills in the community with a nursing agency.
- My love of LTV continued to grow. In late 2017, I started with EACH as a clinical nurse specialist and have supported the growth of LTV within palliative care at EACH and regionally.

Hannah Devereux-Watson: LTV Nurse



- Started at EACH hospice 6 months after qualifying as a Learning Disability Nurse in 2015, in the care team.
- Recognised a 'gap' in robust LTV plans and how to escalate LTV care.
- Began working with LTV service users to build own knowledge and improve quality of care for service users, prior to EACH LTV project beginning.
- Seconded into LTV Nurse role from the care floor in 2016.
- Special interest in complex needs and 'how things work'.
- Key role in delivering internal and external training to paediatric and adult teams, utilising my learning disability qualification to holistically look at the BCYP, their family and setting in which they access.

Charlotte Pipe: LTV Nurse



- Joined EACH in 2012 as a nurse 6 months post-qualification, under the preceptorship programme.
- Keen interest in respiratory care, complex chest management, and long-term ventilation.
- Seconded part-time into the LTV nurse at the latter part of 2016, focusing on the initial rolling out of EACH LTV training and upskilling of staff, following expanding and furthering my skills from time spent at Addenbrookes.
- Became a full-time member in 2017-present, aiding the ongoing workforce in furthering their development, skills, competence, networking with others nationwide, providing both internal and external training, whilst supporting the LTV caseload and LTV team.

Jess Owen: LTV Nurse



- Qualified in 2014 and started working at St George's NICU consolidating skills and building specialist knowledge.
- Moved to the Treehouse in October 2015, where I have either been working as permanent staff or enrolled on the bank since. I continued to maintain up to date in Long Term Ventilation as a Train the Trainer, working tri-site with LTV BCYP.
- Moved to Rainbow Ward at West Suffolk Hospital in January 2021 as a ward sister.
- March 2022, moved to the community as a children's community nurse.
- May 2025 commenced new role as LTV nurse, back within EACH and palliative care.

Jenine Blackford: Associate practitioner for LTV



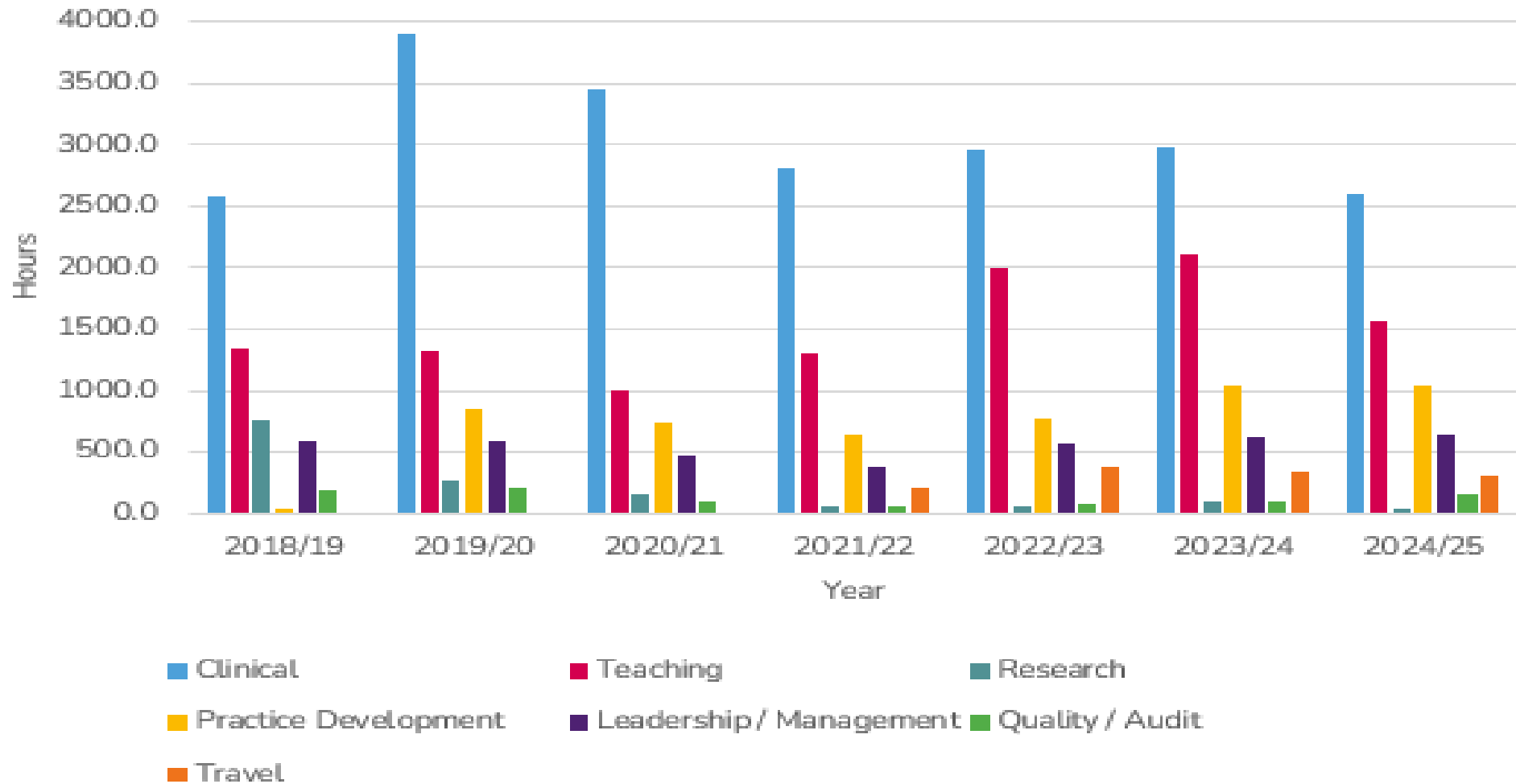
- Worked in the field of LTV since the early 90s, starting at Great Ormond Street on the first ever LTV Transitional Care Unit in the UK.
- Helped to set up the LTV unit at The Children's Trust in Tadworth, Surrey.
- Joined the EACH LTV team in 2018.
- Have a specific interest in invasive airways and am now a qualified Tracheostomy Train the Trainer.
- Completed my BLS course to become a Resuscitation Officer.
- Currently secretary for the National Children's & Young People's LTV Hospice Forum, having restarted the group following the pandemic.

Tina Duffield: Associate practitioner for LTV

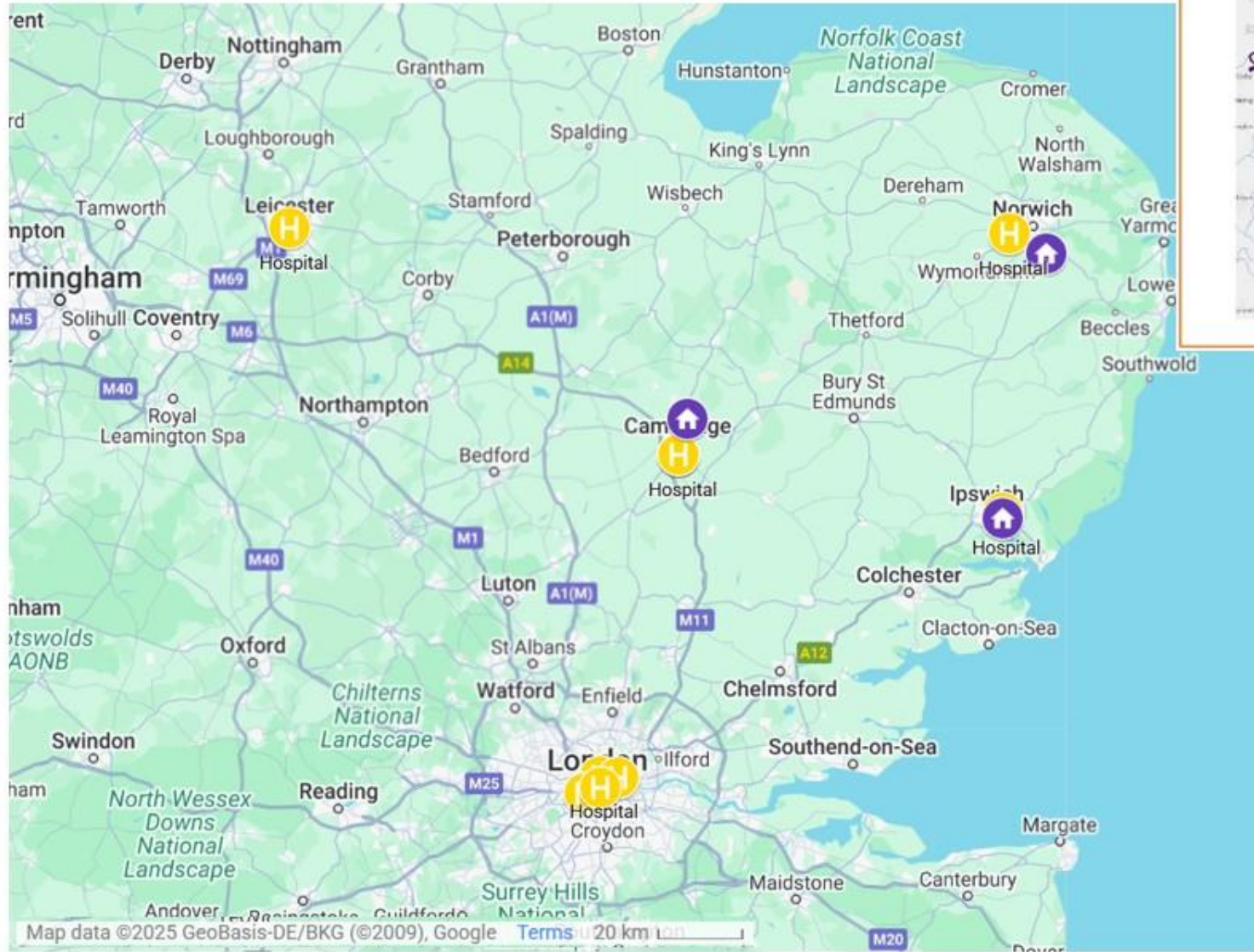


- Keen interest in complex care since college, studying a BTEC in children's development.
- Worked within community home care packages for four years post-college, caring for a young person and an infant both requiring 24/7 invasive ventilation.
- Following this, joined EACH as a care assistant in 2015, and then the LTV team specifically in 2018.
- Since Sept 2024, been enrolled in the Trainee Nursing Associate apprenticeship through EACH. Planning to continue onto the nursing apprenticeship degree post-TNA graduation in 2026.

Total Team Hours by Activity



EACH LTV Team Lead Centres 2025



- Hospital**
 - Cambridge University Hospitals
 - Papworth Hospital
 - Norfolk & Norwich University Hospital
 - Great Ormond Street Hospital
 - Royal Brompton Hospital
 - Leicester Royal Infirmary
 - Ipswich Hospital
 - The Royal London Hospital
 - Evelina London Children's Hospital
- Hospice**
 - EACH, Milton
 - EACH, Nook
 - EACH, Treehouse

Regional impact

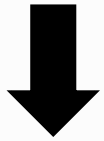
As a service, we started as an extension of the Symptom Management Nursing Service - to provide specialist LTV advice to those LTV BCYP.

Quickly, it became apparent what was needed/wanted by families:

- To fill the important gaps between multiple agencies.
- To advocate for families.
- Provide expert practical and technical LTV support.
- Have the knowledge and understanding of expected standards of specialist LTV care, especially within the context of palliative care and to share this knowledge with teams/services who encounter our LTV BCYP.
- We quickly learnt how widespread this could be. However, we mainly work with their educational settings, social care teams, lead centres, ICB's and care agencies to ensure safe practice and inclusivity regardless of their LTV needs.
- To support LTV and end of life in multiple settings, to take the fear away with an LTV child who is end of life, provide in-person practical and supervisory support.

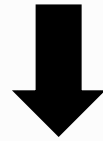
How do we make an impact?

Prevent poor practice by providing charitable and commissioned LTV training



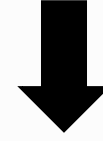
“The LTV training at EACH is an invaluable asset to my learning and development. I have received highly detailed, situational learning in practice that ensures evidence-based current care.”

Prevent the breakdown of care packages by liaising heavily between families, the ICB and social work teams to support needs and resolutions



“They provide us with practical and emotional support....We really couldn't have coped with the transition from hospital to home without their support and have relied on them many times over the years to keep us going.”

Management of LTV needs at EOL, symptom control, ‘good’ death, support of care teams such as DGH hospital or community teams



“Having colleagues with such invaluable knowledge is just incredible. An amazing resource to have when seeking advice regarding children transferring into the hospice for end-of-life care.”

Regional impact of our clinical support

“You are the only team who has always helped in every department!”

“The EACH LTV team has been supportive and responsive, even at short notice, knowing that this is vital for us to be able to support the wonderful CYP in our care.”

“... I actually felt ok and a bit like a ‘weight lifted off my shoulders’ as you brought possible solutions and plans to help move forward rather than the endless going around in circles which we have been doing.”

Regional impact from our training

“The team has been working collaboratively with our service for several years. We support CYP with both TLTV and NIV. EACH’s training has always been exemplary. They are extremely knowledgeable, and the teaching style is accessible and understandable for all learners. No question is out of bounds or daft!”

“The LTV training at EACH is an invaluable asset to my learning and development. I have received highly detailed, situational learning in practice that ensures evidence-based current care.”



Any Questions?



Please use the QR code to access an example of our LTV work