Regional Network Co-ordinator for the Yorkshire and Humber Children and Young People’s Palliative Care Network

Information and recruitment pack

Supported by

Martin House
hospice care for children and young people

Bluebell Wood
Children’s Hospice

forget me not children’s hospice

St Andrew’s Hospice

Leeds South and East
Clinical Commissioning Group
Introduction

Thank you for your interest in the post of Regional Network Co-ordinator for the Yorkshire and Humber Children and Young People’s Palliative Care Network (YHCYPPCN). We hope that you will find all the information you need in this pack to help you decide if you are the right person for this inspiring and exiting role.

The YHCYPPCN is a multi-agency group working together to provide equal, integrated and flexible palliative care for children and young people and their families across Yorkshire and Humberside.

The group has been in existence for a number of years but, over the past 12 months, a number of steps have been taken to refresh and strengthen the network and we have ambitious plans for the future.

The proposed model of future provision of children’s palliative care in the Yorkshire and Humber region is a hub and spoke model of care governed by a funded managed clinical network. There is widespread support for this approach within the children’s palliative care sector but the existing network has no dedicated staff resource and there is insufficient capacity within existing organisations.

It is therefore essential to appoint a Network Co-ordinator to support this development path and lead delivery of the following outcomes:

- To improve the care, support and quality of life for life-limited children and young people and their families in the region by supporting the objectives and activities of the YHCYPPCN; and
- To enable delivery of the Network’s objectives through effective planning, coordination, data management, influencing and networking, communications, consultation and administration.

If, after reading this pack, you have any questions, please contact Rachel Sherbourne, Secretary to the Network. Rachel is contactable on 01937 845045 or rsherbourne@martinhouse.org.uk

Thank you.

Dr Anton Mayer
Chair of the YHCYPPCN
Consultant in Paediatric Palliative Care and Paediatric Intensive Care
**About the Network**

The provision of palliative care for children and young people across Yorkshire and Humberside requires an integrated, multi-agency approach. This provision needs to be from specialist and generic services, from voluntary and statutory providers, and from many professionals across primary, secondary and tertiary care.

The Independent Review of Children’s Palliative Care, chaired by Professor Alan Craft and Sue Killen recommended the formation of established, functioning and effective regional Paediatric Palliative Care Networks to support service planning and commissioning.

Children’s palliative care does not work in isolation but alongside other health, social care and education services and supports them. Children’s palliative care is part of the wider developments identified in regional and local Children and Young People’s Plans.

Children’s palliative care can start antenatally and be delivered through neonatal, infant, childhood, teenage and young adult stages.

The YHCYPPCN is a multi-agency group working together to provide equal, integrated and flexible palliative care for children and young people and their families across Yorkshire and Humberside. It exists to build a needs-led strategy which guides the delivery of palliative care to children and young people and their families in Yorkshire and Humberside. Delivery is based upon the principles of collaborative working by organisations to achieve the best outcomes for children, young people and their families.

The remit and function of the YHCYPPCN is to:

- Develop a strategic and integrated approach to the development of local children and young people’s palliative care services and work to improve care provision across the region.
- Develop and keep under review a regional strategy for children and young people’s palliative care in Yorkshire and the Humber, which draws on evidence and best practice in the paediatric palliative care sector.
- Develop an integrated multi-agency care pathway for the provision and delivery of palliative care for babies, children and young people.
- Implement the Yorkshire and Humber children and young people’s palliative care strategy alongside national policy guidance.
- Establish effective links with service users’ and carers’ forums and ensure that children, young people and their families can input to and influence the development of policy and services.
- Identify gaps in, or problems with, the service and respond to them.
- Explore and encourage cross-boundary working partnerships and sharing of good practice and expertise.
- Agree working groups to implement the work plan.
- Promote children and young people’s palliative care and ensure that Clinical Commissioning Groups and Health and Wellbeing Boards give it the prominence it requires.
- Ensure there is a shared accountability and self-governance across the members of the group.
- Establish effective links and working arrangements with the Yorkshire and Humber Children and Maternity Strategic Clinical Network and other relevant commissioning networks.
- Provide a sharing and supportive forum for professionals working in children and young people’s palliative care and contribute to the body of knowledge in relation to children and young people’s palliative care.
Its membership includes:

- Commissioners of children and young people’s palliative care services – including CCGs and local authorities
- Paediatric consultants with an interest in palliative care
- Children’s community nurses
- Nurse specialists in children’s palliative care
- Children’s hospices
- Higher education
- Yorkshire Ambulance service and Embrace
- Child education, including special schools
- Adult Palliative Care
- Neonatal network
- Cancer network
- GPs
- Academia
- Together for Short Lives

The full Network meets twice a year and links in with both Together for Short Lives and the National Forum of Networks. It develops and leads a yearly conference on Children’s Palliative Care in the region.

**The Network Executive**

The Network is overseen by an Executive Group which oversee delivery and drive forward the strategy. This group meets quarterly and its membership comprises:

- Chief Executives of children’s hospices (Angela Monaghan of Martin House, Claire Rintoul of Bluebell Wood and Peter Branson of Forget Me Not)
- Medical Consultant in Paediatric Palliative Care (Dr Anton Mayer, Consultant for Paediatric Palliative Care and Paediatric Intensive Care, Sheffield Children’s Hospital and Bluebell Wood Hospice)
- Medical Consultant with an interest in palliative care (Dr Claire Wensley, Consultant Paediatrician at York Hospital)
- Directors of Care of children’s Hospices (Michelle Rollinson of St Andrew’s and Sharon Burton of Forget Me Not)
- Nurse Consultant (Liz Lyles of Forget Me Not)
- Children’s Community Nurse (tbc)
- Specialist Nurse in CPC (Danielle Lewis and Helen Storton, Children’s Palliative Nurse Specialists at BTHT)
- Representative from Together for Short Lives (Jane Houghton, Practice and Service Development Manager)
- CCG representative (tbc)
- Research representative (Lorna Fraser, Department of Health Sciences, University of York)
- Education representative (Liz Webster, Director of Care at Bluebell Wood)

**The Network’s sub-groups**

Two sub-groups report to the Network; a Clinical and Research group and a Workforce and Education Group. The Chair of each group sits on the Executive.
The Clinical and Research group aims to ensure that the Network is able to share and support best practice in paediatric palliative clinical care and is a research active network.

The Workforce and Education group aims to identify the requirements and lead the development of multi-professional education and training and workforce planning for children and young person’s palliative care across Yorkshire and Humber. The group will influence regional and national priority setting in these areas.

**Children and Young People with Life-Limiting Conditions**

There are more than 40,000 children and young people aged 0-19 years living with a Life Limiting Condition (LLC) in England and this number is rising. LLC are conditions for which there is no reasonable hope of cure and from which children or young people will die, and include life-threatening conditions for which curative treatment may be feasible but can fail, such as cancer or heart failure. More than 300 diagnoses are considered as LLC in children and include Duchenne muscular dystrophy, severe cerebral palsy, the leukodystrophies and severe congenital anomalies. Although many of the individual diagnoses are rare, as a group children and young people with a LLC are a larger patient population than many other long term conditions in children and young people for example diabetes mellitus where 23,719 CYP (0-19 years) were reported in England in 2012/13.

One of the main reasons for the increasing numbers of children and young people with a LLC is the increased survival in some of these children via more aggressive management of complications and use of medical technologies such as home ventilation. Children and young people with a LLC should have access to children’s palliative care services.

Children’s palliative care is defined by Together for Short Lives, the national charity for children and young people with life-limiting and life threatening conditions as “An active and total approach to care, from the point of diagnosis or recognition, throughout the child’s life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement”.

There are 1,280,663 children and young people aged less than 19 years living in the Yorkshire and Humber. The prevalence of LLC in children and young people in the Yorkshire and Humber was estimated to be 29.7 per 10000 (n=3741) in 2009/10. This prevalence varied over the region with the highest prevalence in Bradford (42.4 per 10000). End of life care is one aspect of children’s palliative care that should be provided and there were 604 deaths in children and young people under 25 years of age in the Yorkshire and Humber region in 2012. 403 deaths were in children aged 0-14 years of age and 201 deaths were in young people aged between 15-24 years. Deaths of children diagnosed with life-limiting disorders might account for 50% or more of all child mortality in England and Wales.

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Provision of Specialist Paediatric Palliative Care in Yorkshire and Humber

A report was commissioned by the YHCYPPCN and published in 2015 to assess the current provision of specialist children’s palliative care in the Yorkshire and Humber region, identify gaps and make recommendations for future service provision.

Current children’s palliative care is provided by four children’s hospice providers, two tertiary paediatric hospitals and 16 district general hospitals from which community children’s nursing teams work. The vast majority of specialist paediatric palliative care in Yorkshire and the Humber is provided by charity funded organisations. There is an active strategic network for Children and Young People’s palliative care in Yorkshire and the Humber.

Current gaps in service include:

- large gaps in the provision of 24 hours 7 day a week services across the region.
- incomplete provision of medical cover in the four children’s hospices.
- lack of formal arrangements for provision of end of life care in the majority of the region.
- lack of formal commissioning of these services.
- inequity in the provision of services for children without oncology diagnoses in some parts of the Yorkshire and Humber region.

The proposed model of future provision of children’s palliative care in the Yorkshire and Humber region arising from this report was a hub and spoke model of care governed by a funded managed clinical network. This managed clinical network would be led by a lead clinician (level 4) and nurse specialist in children’s palliative care.

The recommendations are of joint commissioning between the current service providers and the CCGs to provide the hub and spoke model of care. The development of the full hub and spoke model will take several years, therefore a phased approach is proposed, which would require co-commissioning between the current service providers and the CCGs, to:

- establish a managed clinical network for children’s palliative care services in Yorkshire and the Humber and to develop a strategy for delivering this 24/7 service (within 12 months).
- develop a hub and spoke model of delivering children’s palliative care (within 12 months).
- work towards having a clinical lead for children’s palliative care in the areas covered by the 16 District General Hospitals and 2 tertiary children’s hospitals in Yorkshire and the Humber (within 12 months).
- work towards having a lead nurse children’s palliative care in the areas covered by the 16 District General Hospitals and 2 tertiary children’s hospitals in Yorkshire and the Humber (within 12 months).
- develop a regional Children’s Palliative Care Register (within 36 months).

It is to lead the Network in the delivery of these objectives that we are seeking to appoint a Regional Network Co-ordinator.

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3 Fraser L, Monaghan A, Mayer A. 2015. Provision of Specialist Paediatric Palliative Care in Yorkshire and Humber
About the job

We are seeking someone with strong networking, project management and planning skills, who is an effective communicator, both verbally and in writing, and has a strong interest in health and social care, especially children’s palliative care.

The responsibilities and duties are set out overleaf but the main purpose of the role is to improve the care, support and quality of life for life-limited children and young people and their families in the region by supporting the objectives and activities of the YHCYPPCN and to enable delivery of the Network’s objectives through effective planning, co-ordination, influencing and networking, communications, consultation and administration.

The Regional Network Co-ordinator will be accountable to Martin House, as the employing body, and report to the Network Executive Group.

The post, which is for two years initially with continuation subject to funding, is funded by Leeds CCGs and the four supporting hospices; Martin House, Bluebell Wood, Forget Me Not and St Andrew’s.

The post holder will be home-based within the Yorkshire and Humber region with access to a hot desk in each of the supporting hospices. A laptop will be provided.
Job description

Job Title: Regional Network Co-ordinator

Salary: £31,383-41,373 dependent on experience

Hours: 37.5 per week. Occasional out of hours work may be required.

Term: 2 years initially – continuation subject to funding – with probationary period of 3 months.

Accountability: Accountable to the employing body, Martin House. Reports to the Network Executive Group via an appointed representative/line manager.

Location: Home-based within the Yorkshire and Humber region with access to a hot desk in each of the supporting hospices (Bluebell Wood, Forget Me Not, Martin House and St. Andrew’s)

Secondment may be considered for the right candidate

Job Purpose:
- To improve the care, support and quality of life for life-limited children and young people and their families in the region by supporting the objectives and activities of the Yorkshire and Humber Children’s and Young People’s Palliative Care Network (YHCYPPCN).
- To enable delivery of the Network’s objectives through effective planning, coordination, data management, influencing and networking, communications, consultation and administration.

Responsibilities and Duties

Strategy and Planning
- Lead and coordinate the development of a regional strategy for children and young people’s palliative care.
- Develop project plans and budgets to support the delivery of the Network’s objectives.
- Identify and manage risks associated with delivery of the Network’s objectives.

Coordination and Administration
- Coordinate and administer meetings of the Network, Executive Group and Sub Groups.
- Ensure delivery of project plans. This includes coordinating the work of others in addition to personally undertaking actions.
- Manage and report on Network budget.
- Monitor progress against agreed outputs and outcomes and provide quarterly reports to the Network Executive Group.
- Support projects aimed at delivering improvements to paediatric palliative care across the region through changes in practice, training or policy documents.
Networking, Communication and Consultation

- Develop and maintain a website and social media channels for the Network.
- Engage with, influence and involve relevant partners and stakeholders to support delivery of the objectives, including NHS providers, CCGs, NHS England, local authorities, HEE, hospices, other relevant networks, plus other partners from the statutory, private and voluntary sectors.
- Encourage and support service improvement through the sharing of good practice and partnership working at regional and national level.
- Promote and enable service user involvement and coordinate consultations with stakeholders and service users on behalf of the Network.
- Produce briefings and updates to Network members, partners and stakeholders using a range of relevant methods and media.
- Promote the work of the Network regionally and nationally and share good practice and learning.
- Coordinate responses to policy and practice developments relevant to children and young people’s palliative care on behalf of the Network.
- Plan and coordinate delivery of annual conference and other events in support of the Network’s objectives.

Business Development

- Identify and develop new business opportunities with any of the system partners in health and social care (e.g. NHS England, CCGs, local authorities, etc.)
- Develop proposals and funding bids to secure future funding for the Network.

General

- Value equality and diversity and comply with relevant equality legislation at all times.
- Attend meetings with appointed line manager as required.
- Attend all relevant mandatory training and any other education and training considered necessary to carry out the role, and take responsibility for one’s own personal development.
- Cooperate with colleagues, encourage and support positive working relationships and foster a culture of respect and consideration at work.
- Take responsibility for one’s own health and safety and the health and safety of others whilst at work and comply with Health and Safety legislation.
- Comply with all information governance requirements and maintain confidentiality at all times, as required.
- Promote and maintain a positive image and reputation for the Network.
- Comply with the policies and procedures of the employing body.
- This Job Description is not exhaustive and the role may require other duties. It will be subject to periodic review and may be amended following discussion between the post-holder and employer.
## Person specification

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<th>Requirement</th>
<th>Essential</th>
<th>Desirable</th>
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<td>Qualifications</td>
<td>◦ Degree or equivalent</td>
<td>◦ Children and young people’s palliative care</td>
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<td>◦ Networking and collaborative working with multi-disciplinary and cross-sector teams</td>
<td>◦ Working in health or social care</td>
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<td>◦ Project management</td>
<td>◦ Developing and implementing successful consultations</td>
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<td>◦ Strategic planning</td>
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<td>◦ Budget management</td>
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<td>◦ Marketing and communication</td>
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<td>◦ Risk management</td>
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<td>Experience of</td>
<td>◦ Children and young people’s palliative care</td>
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<td>Knowledge of</td>
<td>◦ The benefits and strengths of collaborative and partnership working</td>
<td>◦ Data sharing in health care</td>
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<td>◦ Good governance</td>
<td>◦ Managed clinical networks</td>
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<td>Skills</td>
<td>◦ Proven planning and coordination skills</td>
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<td>◦ Networking and influencing skills</td>
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<td>◦ Excellent verbal and written communication skills, with attention to detail</td>
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<td>◦ Ability to analyse and synthesise complex information and to present this in summary form to a range of target audiences</td>
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<td>◦ Excellent organisational and time management skills with the ability to respond to changing and competing demands</td>
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<td>◦ Strong IT skills, including use of social media</td>
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<td>Personal attributes</td>
<td>◦ Proven ability to engage confidently and positively with a wide range of people and organisations, including voluntary groups, statutory bodies, clinicians, and children, young people and their families</td>
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<td>◦ Self-motivated and able to work effectively alone and without supervision</td>
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<td>◦ Committed to equal opportunities for all, to tackling disadvantage and promoting diversity</td>
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<td>◦ Strong interest in health and social care</td>
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<td>◦ Willing and able to work from home and travel across the Yorkshire and Humber region, London and elsewhere in England</td>
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**Main Benefits, Terms and Conditions**

**Annual leave**: the annual leave entitlement is 25 days per annum plus bank holiday.

**Pension**: the Martin House stakeholder pension scheme currently has employee contributions of 2.5% and employer contributions of 4.25%. Staff joining Martin House from the NHS may continue with their NHS pension.

**Sickness**: is paid at 3 months full pay and 3 months half pay.

**Childcare Voucher Scheme**: Martin House offers a childcare voucher scheme.

**Employee Assistance Programme**: all staff and their families are eligible to access a free and confidential employee assistance programme offering support, information and counselling.

**Healthcare Scheme**: staff can access the SimplyHealth healthcare scheme at discounted rates.

**Life Assurance**: all staff have death in service cover of 2 years’ salary.

**Notice period**: 3 months.

**How to apply**

If you are interested in this position, please complete an application form, referring to the job description and person specification. This is available on our website (www.martinhouse.org.uk) or by contacting Rachel Sherbourne at Martin House (rsherbourne@martinhouse.org.uk or 01937 845045).

The closing date for applications is **12 noon on Friday 16th December**. Email applications should be sent to Rachel at rsherbourne@martinhouse.org.uk

Successful shortlisted candidates will be contacted by Friday 23rd December and interviews will take place at Martin House on **Tuesday 10th January 2017**.