

# North Star

Newsletter of the Northwest  
Children's Palliative Care Network



Autumn 2014

## From the Chair...

Welcome to the Autumn edition of **North Star**, the newsletter for the Northwest Children's Palliative Care Network.

The Northwest Children's Palliative Care Network brings together representatives of babies, children and young people with palliative care needs and their families, commissioners and providers of children's palliative care from NHS, Voluntary sectors, Social Services and Education, across primary, secondary and tertiary care with the aim of improving co-ordination availability and delivery of palliative care.

We hope that this newsletter will help to raise awareness of the Network and allow more children, families, commissioners and providers of services to join with us in our work.

In this edition you will find information about the work of the Network and opportunities for you to participate and feedback.

We are delighted to report that the Network Website will be launched at the Networks Conference on 16th October. More information is available about the website in this edition

**A HUGE thankyou to Anna Oddy, Lis Meates and Shirley Potts who provided articles for this edition.** Contributions for future editions of the newsletter are very much appreciated.

In the meantime if you want to find out more about the Network please don't hesitate to contact me on [Lynda.Brook@alderhey.nhs.uk](mailto:Lynda.Brook@alderhey.nhs.uk)

Important forthcoming events:



Northwest Children's Network's Conference on 16th October, Partnership for Learning Centre, Speke

Next Network meeting  
Friday 5th December  
10:30—13:00  
Francis House Hospice,  
Manchester, M20 5NA

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## Launch of the Northwest Children's Unified DNA-CPR Policy and Advance Care Planning Implementation Group

The Northwest Children's Unified DNA-CPR Policy and Advance Care Planning Implementation Group aims to provide a forum for

- Local support and implementation of the Children's Unified DNA-CPR Policy and Advance Care Plan
- Review and updating of the Children's Advance

Care Plan documentation template

- Implementation of the 3 level Advance Care Planning training programme
- Auditing outcomes when Advance Care Plans are used to support children accessing urgent care

The group is being chaired

by Peter-Marc Fortune and will meet quarterly.

The first meeting is on 31st October 10:00—12:00, NWTS Warrington WA3 6FW.

For more information please contact Peter-  
[Marc.Fortune@cmft.nhs.uk](mailto:Marc.Fortune@cmft.nhs.uk)  
0161 701 8042

## Northwest Children's Palliative Care Network Strategy 2015–17



The Northwest Children's Palliative Care Strategy 2015–17, **Engagement, Education and Empowerment**, will be launched at the Northwest Children's Networks Conference on 16th October. The Strategy has been developed through the work of Parent Voices Count in partnership with the Northwest Children's Palliative Care Network and builds on the work of the 2011-14 Strategy.

Key deliverables include a programme of **engagement meetings and events**

- Parent Voices Count drop

in events, website, newsletter, workshops

- Meetings with organisational leaders and strategic partners
- Engaging professionals building on Locality Workshops and developing palliative care education standards for the network

**Education** through

- Development of a **Family Services Directory**

- Briefings and follow up for organisational leaders and strategic partners

- Delivery of the **Network**

### Education Programme

And **empowerment** as

- Parent Voices will be heard!
- Organisational leaders and strategic partners will sign up to the statement of commitment and support Parent Voices Count, support Network Education Standards, and support children's palliative care data collection
- Professionals will have essential palliative care skills and competencies

Information [Lynda.Brook@alderhey.nhs.uk](mailto:Lynda.Brook@alderhey.nhs.uk)

*“EHC Plans replace the current system of Individual Healthcare Plans (IHPs) and Statements of Special Educational Needs.”*

## SEND Reforms and Palliative Care across the Northwest

The Together for Short Lives – SEND, (Special Educational Needs and Disability) Briefing Event in Manchester on 30<sup>th</sup> June 2014 was very well attended by professionals from health, education, social care and the voluntary sector from across the North West. Discussions centred around how the Education Health and Care (EHC) Plans are being introduced across England & Wales during 2014 from birth to

25yrs, and an example of EHC's in practice from one of the pathfinder area. EHC Plans replace the current system of Individual Healthcare Plans (IHPs) and Statements of Special Educational Needs.

Current challenges for children with life limiting conditions and their families were discussed. The Nottinghamshire pathfinder was presented as an example of how children and their fami-

lies can become partners in the care planning process, and be supported and empowered, through joint funding and personalized. Find the Nottinghamshire SEND local offer and other useful resources at

[http://nottinghamshire.sendlocaloffer.org.uk/kb5/nottinghamshire/fsd/local\\_offer.page](http://nottinghamshire.sendlocaloffer.org.uk/kb5/nottinghamshire/fsd/local_offer.page)

*Report by Lis Meates*

## ‘Journeys’: documents to support children’s palliative care

‘Journeys’ is a suite of documents, supported by a model of care and designed to support professionals caring for babies, children and young people with palliative care needs on their journey from diagnosis to end of life care and bereavement.

Journeys’ contains a range of practical resources based on symptoms and needs rather than diagnoses.

Documents include forms, checklists and information sheets, organised in sections reflecting the needs of the child and their family during different stages of their journey: diagnosis or recognition, living with a life limiting condition, end of life care and bereavement.

Resources are presented a framework, based on the format of the West Midlands’ Toolkit, designed to be downloaded and

adapted by individual teams.

Journeys will be available to download from the Northwest Network website.

For more information contact [Anna.Oddy@nhs.net](mailto:Anna.Oddy@nhs.net)



## Improving Bereavement Services in the Northwest

Child Bereavement UK (CBUK) is undertaking a 3 year DH-funded project to improve bereavement support in 6 of England's most deprived areas. In Liverpool and other areas across the UK, CBUK has set up a Childhood Bereavement Advisory Group with the intention of keeping bereavement issues on the local agenda beyond the life of the current project.

The project is improving signposting to local agencies, through awareness-raising and developing a

route-map of support ranging from informal support through school, friends and family to designated bereavement services. The team has devised a template bereavement policy for schools and worked with voluntary and statutory agencies to emphasise the significance of timely bereavement support. The team has also presented local study days as well as raising awareness of the range of courses, website and helpline provided by Child Bereavement UK.

The project aims to leave each area with empowered, informed practitioners with a greater understanding of the needs of bereaved people as well as a wider knowledge of what is available in their locality.

We are grateful to a wide range of colleagues and organisations that have supported our efforts and shared their experience with us.

*Shirley Potts, Director of Regional Development,*  
[www.childbereavementuk.org](http://www.childbereavementuk.org)



## Making more Parent Voices Count!

Parent voices count held its first parent participation day in Manchester on 12th July.

The event, presented by Parent Voices Count in partnership with providers of services for children with palliative care needs, featured display stands from a wide range of NHS and voluntary sector services available to support children with palliative care needs in the area. Activities for chil-

dren included a Clown Doctor, arts and crafts activities, stories, a soft play area and light room. Parents and carers were able to take part in a range of participation activities designed to develop and prioritise the "to do list" developed by Parent Voices Count as well as providing opportunities for further feedback. Families were also encouraged to continue with participation activities by joining the Parent Voices Count

meetings and visiting the website.

Although family attendance was lower than expected, Parent Voices Count has identified that further similar smaller scale events are an important way of raising the profile of Parent Voices Count and increasing parent and carer participation.

Contact [Lizzi.Aizlewood@alderhey.nhs.uk](mailto:Lizzi.Aizlewood@alderhey.nhs.uk) for more information.

*"Parents and carers were able to take part in a range of participation activities..."*

## Network Website Launch

The Northwest Children's Palliative Care Network Website will be launched at the Northwest Networks Conference on 16th October. The website which has been designed by Parent Voices Count Facilitator Lizzi Aizlewood is set to become the hub of communication and resources for the Network.

The Website will include a home page with details of the Network Vision and

Strategy, the geographical area covered by the Network and contact details. Each of the Zonal Networks will have their own dedicated web pages. There will also be pages for Education and Training, Northwest Children's Palliative Care Research and Data Groups. The Website will also feature a resources area where Network members can access important documents such as the Rapid Discharge Pathway, Advance

Care Plan templates and hyperlinks to other important resources on external sites like Together for Short Lives and the Association for Paediatric Palliative Medicine.

General website content of will be visible to everyone. However professionals will need to register with the Network in order to access resources.

Contact [Lizi.Aizlewood@alderhey.nhs.uk](mailto:Lizi.Aizlewood@alderhey.nhs.uk)



**NORTHWEST  
CHILDREN'S  
PALLIATIVE CARE  
NETWORK**

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## Joining Together

### Northwest Children and Young People's Palliative Care Network: Mission Statement

"All babies, children and young people with life threatening and life limiting conditions, and their families will have access to the highest quality of supportive and palliative care throughout their journey from diagnosis to bereavement or transition to adult services. This will be provided in the most appropriate place according to needs and wishes of the child and family, regardless of geographical location, cultural social or ethnic factors. There will be full integration of services with seamless transition of care between primary, secondary and tertiary healthcare settings and close partnership between healthcare, education and social services care."

The main focus of the Northwest Children and Young People's Palliative Network is babies, children and young people from 0 to 19 years but also includes antenatal diagnosis

### Events, Education and Training

22nd & 23rd September **Advanced Communication Skills**, ManCEL Centre  
[Melanie.Lowe@cmft.nhs.uk](mailto:Melanie.Lowe@cmft.nhs.uk)

2nd October, **Together for Short Lives Networks Summit**, Salford  
[Nicole.Harper@togetherforshortlives.org.uk](mailto:Nicole.Harper@togetherforshortlives.org.uk)

14th October, 21st October, 11th November & 9th December; **Leading a single education health and care plan** key-working course, [cpdenquiries@edgehill.ac.uk](mailto:cpdenquiries@edgehill.ac.uk)

16th October **Network's Conference** Partnership for Learning Centre, Speke  
[Louise.King@cmft.nhs.uk](mailto:Louise.King@cmft.nhs.uk)

16th October, **Royal Society for Medicine Paediatric Palliative Care Outcomes conference**, Alder Hey Children's Hospital, [palliative@rsm.ac.uk](mailto:palliative@rsm.ac.uk)

23rd October **Advance Care Planning Study Day**, ManCEL Centre  
[Melanie.Lowe@cmft.nhs.uk](mailto:Melanie.Lowe@cmft.nhs.uk)

3rd and 4th November **Advanced Communication Skills**, ManCEL Centre  
[Melanie.Lowe@cmft.nhs.uk](mailto:Melanie.Lowe@cmft.nhs.uk))

27th November **Together for Short Lives Leaders of Care Conference**, Park Crescent Centre, Gt Portland Street, London [nicole.harper@togetherforshortlives.org.uk](mailto:nicole.harper@togetherforshortlives.org.uk)

28th November **Association for Paediatric Palliative Medicine Study Day**, Park Crescent Centre, Gt Portland Street, London [nicole.harper@togetherforshortlives.org.uk](mailto:nicole.harper@togetherforshortlives.org.uk)

29th January 2015 **One Day Advanced Course in Paediatric Palliative Care**, Bury Hospice [Lynda.Brook@alderhey.nhs.uk](mailto:Lynda.Brook@alderhey.nhs.uk)

30th January 2015 **Update in Paediatric Palliative Care**, Bury Hospice  
[Lynda.Brook@alderhey.nhs.uk](mailto:Lynda.Brook@alderhey.nhs.uk)

**Northwest Paediatric Palliative Care Forum** [Sharon.Townsend@alderhey.nhs.uk](mailto:Sharon.Townsend@alderhey.nhs.uk)

Practical End of Life Care, 13:00– 16:15, 18th September, Alder Hey Children's Hospital

Stress and burnout, 25th November, 13:00– 16:15, Central Manchester Teaching Hospitals

**Northwest Children's Palliative Care Network** [Lynda.Brook@alderhey.nhs.uk](mailto:Lynda.Brook@alderhey.nhs.uk)

Friday 5th December 2014 10:30—13:00, Francis House Hospice, Manchester

Friday 6th March 2015 10:30—13:00, Venue to be confirmed

