

# North Star

Newsletter of the Northwest  
Children's Palliative Care Network



Summer 2014

## From the Chair...

Welcome to very first 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 hope to have a Network website up and running soon.

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:

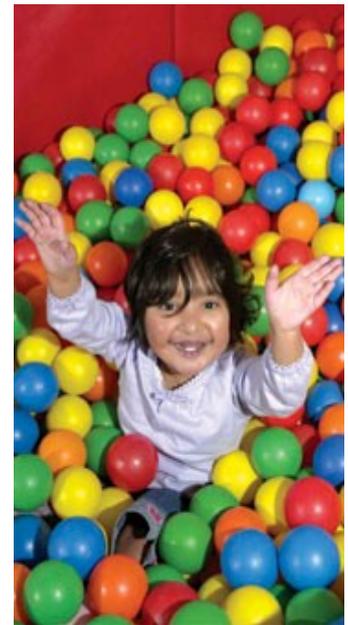
Network's Conference on 16th October,

Partnership for Learning Centre, Speke

Next Network meeting

Friday 6th September  
10:30—13:00

Zoe's Place Baby Hospice,  
Liverpool, L12 9HH



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## Parent Voices Count! Family participation day 12th July

Parent Voices Count! first Family Participation day is on Saturday 12th July at 1pm – 4 pm at Redbank House 4 St Chads Street, Cheetham, Manchester, M8 8QA. All are welcome.

Parent Voices Count! Is a group of parents who in recent years have been told that their child has a life threatening illness and

have experienced children's palliative care.

Parents and carers know what it's like to have a child with a life threatening or life shortening condition and can advise professionals on exactly what they think is needed.

• Parents can be involved by: Coming to our monthly

meetings.

- Joining a project.
- Giving your feedback by email, text or phone.
- Or simply by receiving news and updates

[www.parent-voices-count.org.uk](http://www.parent-voices-count.org.uk)

[parentvoices.count@nhs.net](mailto:parentvoices.count@nhs.net)

07516943856

## Improving Advance Care Planning across the Northwest



The Children's Advance Care Plan is a tool for discussing and communicating information about a child's healthcare needs and the child and family's wishes for future care. The Advance Care Plan helps ensure that the child receives the most appropriate care. It should also reduce the number of times a family have to tell and retell their story. The Advance Care Plan is particularly useful in an emergency when the individual cannot give informed consent for themselves and/or

parents cannot be contacted.

A new standard format Advance Care Plan and Unified DNA-CPR policy is being introduced across the whole of the Northwest. The child and family will hold a paper copy of the Advance Care Plan. Electronic or paper copies will be distributed via named professionals to services likely to come into contact with the child such as their GP, local A&E and community nurses. The Plan will be co-ordinated by a named

professional, known to the child and family, who will take overall responsibility for the child's Advance Care Plan and ensuring it is updated regularly.

Implementation of the Children's Advance Care Plan and unified DNA-CPR policy and is supported by a three level training programme.

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

***“Funding to make palliative care teams accessible at any time of the day or night, seven days a week”***

## A dead end for the Liverpool Care Pathway?

The Northwest Children's Palliative Care network is using the recommendations of Independent Review of the Liverpool Care Pathway to inform the forthcoming northwest network strategy, ensuring that children across the Northwest receive the best possible end of life care.

Key recommendations include

- Identifying a senior clinician and a registered nurse accountable and responsible for each dying patient
- Ensuring the care plan including decisions regarding attempting cardiopulmonary resuscitation are discussed with relatives and carers.
- Appropriate use of medically assisted nutrition and hydration
- Appropriate pain management and sedation

● Funding to make palliative care teams accessible at any time of the day or night, seven days a week, both in hospitals and in community settings.

● Communication skills training for staff involved in end of life care

The Network will work with service users, commissioners and providers to ensure that these requirements are universally met for babies children and young people

## Locality Workshops next steps...

Over the last couple of years the Northwest Children's Palliative Care Network has facilitated Locality workshops with the aim of engaging key stakeholders in planning provision and evaluation of services for children with palliative care needs in each locality area, identifying local priorities and identifying local champions including lead paediatricians and lead nurses in each acute unit.

The workshops themselves were extremely effective engaging local providers, providing events that were very well attended and meeting identified educational needs. Unfortunately it has proven more difficult to sustain the momentum particularly without a dedicated facilitator. However the collective outputs from all the workshops and key themes identified will be used to inform the new Northwest

Children's Palliative Care Network Strategy due to be launched at the Networks conference on 16th October.

So far six workshops have been held across the Northwest

A further Locality workshop will be held in Alder Hey Children's Hospital on 2nd December and a further Locality Workshop is also planned for Lancashire and South Cumbria in the Autumn.

## Palliative Care Funding Review update

Many many thanks to everyone who contributed to the Northwest Children's Palliative Care Funding Review (PCFR) pilot. It was an immense undertaking. Despite all the problems we had we managed to deliver data for a credible 200+ completed Spells.

Although PCFR data collection is finished. The National PCFR steering group will continue to meet. We will link in with this as a Network and provide feedback as and when more information on the proposed

tariff is available

The Northwest Children's Palliative Care Data Group has been developed from the Northwest PCFR steering group and includes a number of new members.

The aims of the group are to support for collection of data on children with palliative care needs across the Northwest and the services they are receiving. This will be achieved through the Database of Serious and Potentially Life Threatening Conditions established to

support the PCFR.

One of the biggest challenges for the group is professional anxiety about approaching families for consent. The **workshop at Leigh on 27<sup>th</sup> June** will address this in more detail. Members of the Northwest Children's Palliative Care Network are welcome.

Please contact

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

## New Northwest Neonatal Palliative Care Guidelines

The appointment of a neonatologist with a special interest has brought new interest in neonatal palliative care.

In the Northwest and across the UK the importance of neonatal palliative care is gaining greater recognition. Following the publication of the Together for Short Lives Neonatal palliative care guidelines and the British Association for Perinatal Medicine (BAPM) Guide-

lines neonatologists, and children's palliative care services are beginning to work together to improve provision of care for babies with life threatening and life shortening conditions.

The Northwest Neonatal networks have recognized the need to develop regional neonatal palliative care guidelines.

Dr Fauzia Paize, a neonatologist with a specialist interest in palliative care

has been recently appointed at Liverpool Women's Hospital. Fauzia has been asked by the Neonatal Networks to lead this project and is currently working to identify individuals and organisations with a specific interest in neonatal palliative care to form a working group.

For more information please contact [Fauzia.Paize@lwh.nhs.uk](mailto:Fauzia.Paize@lwh.nhs.uk)

*“Northwest neonatal networks have recognized the need to develop palliative care guidelines”*

## Northwest Children's Palliative Care Research Group

The Children's Palliative care research group brings together individuals with an interest in paediatric palliative care research with the aim of stimulating and supporting new research initiatives.

The Research Group met at the end of May. Projects that were discussed included

- Strong opiates in end of life care at home for dying

children

- Computers for communication in children's palliative care (ComCChiP)
- Feeding and nutrition in children's palliative care
- An evaluation of the Star Team siblings project

The group will meet again in the Autumn and further dates will be circulated for the academic year 2014 – 15 shortly.

Provisional dates are

- 10th October 2014
- 3<sup>th</sup> February and
- 22<sup>nd</sup> May 2015

Meetings are held at Manchester University. Anyone with an interest in paediatric palliative care research is welcome to attend



**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 and young people aged 19 and over in transition to adult services.

## Events, Education and Training

30th June, **SEND Network Event**, Portland Hotel Manchester, M1 6DP  
([lou.jones@togetherforshortlives.org.uk](mailto:lou.jones@togetherforshortlives.org.uk))

12th July **Parent Voices Count first Family Participation day** 13:00—16:00, Redbank House, 4 St Chads Street, Cheetham, Manchester, M8 8QA. [parentvoices.count@nhs.net](mailto:parentvoices.count@nhs.net)

14th September, 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)

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

2<sup>nd</sup> October, **Together for Short Lives Networks Summit**, Salford  
([Lynda.Brook@alderhey.nhs.uk](mailto:Lynda.Brook@alderhey.nhs.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, L12 2AP ([cdb@runbox.com](mailto:cdb@runbox.com))

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))

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

Palliative care in a multicultural society, 26th June, 13:00– 16:15 Central Manchester Teaching Hospitals

Topic to be confirmed, 13:00– 16:15, 18th September, Alder Hey Children's Hospital

Stress and burnout, 25/11/2014, 13:00– 16:15, , Central Manchester Teaching Hospitals

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Friday 6th September 10:30—13:00, Zoe's Place Baby Hospice

Friday 6th December 10:30—13:00, Lancashire, venue to be confirmed

