

North Star

Newsletter of the Northwest
Children's Palliative Care Network



Winter 2014

From the Chair...

Welcome to the Christmas 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.

This edition is an opportunity to say a special **thankyou to everyone who has contributed to the work of the Network over the last year.**

Without your continued energy, enthusiasm and commitment, despite significant work pressures, we not be making a difference to the lives of children with palliative care needs and their families across the Northwest.

As well as reading through this newsletter please make sure you visit our website to find out more about the difference we can make together

www.childrenspalliativeNW.org.uk

Thanks also to everyone who contributed to this newsletter.

Merry Christmas and a Happy New Year



To find out more about the Network please don't hesitate to contact me on Lynda.Brook@alderhey.nhs.uk

Important forthcoming events:

Next Network meeting
Friday 6th March 10:30—
13:00, Francis House-
Hospice, Manchester, M20
5NA

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Re-energizing the Lancashire and South Cumbria Network

The Lancashire and South Cumbria Network re-convened on 6th November at Preston. The group included strong representation from Preston and also Brian house but unfortunately no-one from Derian House was able to attend. The group undertook a SWAT analysis of children's palliative care in Lancashire and South

Cumbria, considered the purpose and potential benefits of the Network and undertook a brief stakeholder mapping exercise. The plan is to continue to meet quarterly and in the first instance to work on a Locality Workshop in order to raise awareness of children's palliative care, engage further stakeholders, identify priorities for

the Zonal Network and ideally identify a new chair. Meetings will be chaired alternatively by Lynda Brook and Jane Houghton until a new chair is identified. The next meeting will be held on Thursday 8th January at Woodlands Chorley (TBC). Professionals from Lancashire and South Cumbria welcome Lynda.Brook@alderhey.nhs.uk

NICE develop guidance for End of Life Care for Children



After significant lobbying the National Institute for Health and Social Care Excellence (NICE) is finally developing guidelines for Paediatric Palliative. Nice guidelines make evidence based recommendations for NHS providers and commissioners. NICE guidance has been pivotal in bringing about change in areas such as Children's Cancer and adult End of Life Care. Hopefully development of NICE Guidance for End of Life Care for Children will have similar benefits. The process for developing

the Guideline for End of Life Care for Babies, Children and Young People began in the summer, with the appointment of Dr David Vickers as chair of the guideline development group (GDG). The final scope will be published on the website (www.nice.org.uk/guidance/indevelopment/GID-CGWAVE0730) in December. The GDG including health care professionals, parent and patient representatives will start work on the guideline in the New Year. The guideline should be available for consultation in 2016

Stairway to Excellence in Children's Palliative Care



Bev Walley, Community Paediatric Matron and the team from Leighton Hospital in Crewe have developed an innovative approach to raising awareness of children's palliative care and assessing compliance with the Together for Short Lives Core, Neonatal and Transitional Care Pathways. www.togetherforshortlives.org.uk

The concept for the project was that there is no elevator to success in children's palliative

care—you have to take the stairs. A benchmarking exercise focusing on 3 of the key standards from each pathway was undertaken as part of the Aqua Improvement Methodologies training (AIM). It relates to the **individual views and experiences** of medical and nursing staff in the Child and Adolescent Unit, Neonatal Intensive Care Unit and Homecare team, focussing on understanding of practice rather than actual care given

to patients. The project identified particular weaknesses in neonatal discharge planning, child and family centred care; discharge planning for young people, multiagency transition needs assessment and a young person and family centred approach to care. An education and training programme will be developed following analysis of the results of the project. Bev.walley@mcht.nhs.uk

Parent Voices Count: A-Z Guide



Parent Voices Count has been busy over last few months holding meetings and engagement events. They have also produced their first newsletter. During 2015 Parent Voices Count will be working on developing their A-Z Guide for Families and Family Services Directory. The A-Z Guide will take the form of a series of useful hints and tips from one family to another. The questions have been tried out at an engage-

ment event in Manchester and generated a number of positive and enthusiastic responses from parents. Editorial control for the content of the A-Z guide will be held by the Parent Voices Count Group. In order to facilitate this they will draw up some editorial ground rules now to ensure that they can be consistent and appropriate. Hints and tips need to be ethical, safe and culturally and socially acceptable. Contextual information will

be provided where appropriate to help other parents decide whether the advice is relevant to them. The guide will be fully indexed and eventually available on the Parent Voices Count Website. More information is available on the website www.parent-voices-count.org.uk. Replies need to be received by 1st March. Two feedback events are scheduled to review replies and decide on final content for the Guide.

All New Claire House!

Over the last 2 years, Claire House has been almost completely renewed, in order to provide an even better quality of care to children and young people with life-shortening and life-limiting conditions and their families.

The investment of £1.8 million includes dramatically improved Butterfly Suite facilities (special bedrooms for after a child has died), refitted and extended children's bedrooms, including multimedia facilities; a bright, welcoming reception; and some amazing

'immersive technology' that enables children of any ability to play games. We've even updated our facilities for teenagers (we've kept the bar!) and for the first time we have bespoke 1 to 1 and group counselling facilities - particularly important as the families who use Claire House have told us what a difference this service makes to their long-term health.

We hope that as a result of this significant investment, healthcare professionals and other stakeholders will be



even quicker to refer children, young people and families who might benefit from the range

Developing core standards for care packages

The Northwest Children's Palliative Care Network is working to develop Core Standards for Care Packages across the Northwest. The Long Term Ventilation Network is keen to work on this with us, developing the work started at the Network's Conference in October. Scope of the project includes consideration of standards for training of carers and transferability of training across care settings. This is important for patient safety, ensuring a

workforce that can safely in-reach into hospice or hospital and also for families who may take on staff through Personalised Budgets or Direct Payments. Different commissioning arrangements for care packages across the Northwest appear to be the main reason why some carers are able to in-reach. There are important interfaces with discharge planning, transition to adult services, education and training, com-

missioning and uptake of Personalised Budgets and Direct Payments. A small working group would review the outputs from the October conference, information on the Care Certificate and with representatives from the Long Term Ventilation Network, Social Services, Education and Commissioners. The group will produce a working paper to feed back in March 2015 to the Network and other the stakeholders Lynda.brook@alderhey.nhs.uk

“important interfaces with discharge planning, transition to adult services, education and training, commissioning and uptake of Personalised Budgets and Direct Payments”

New APPM Master Formulary

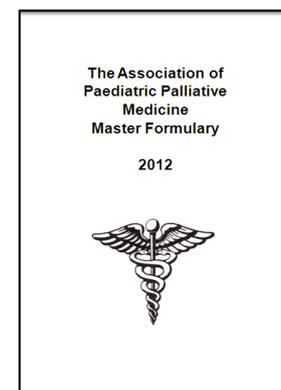
The 2015 edition of the Association for Paediatric Palliative Medicine (APPM) Master Formulary was launched in November at the International Congress in Paediatric Palliative Care in Rome and also at the APPM study day in London.

This third edition of the highly acclaimed formulary aims to become the single “go to” resource for comprehensive prescribing guidance in paediatric palliative care.

This new edition has been extensively re-written and updated. The content has been expanded to include key practice points and information on licensing status. It provides validated evidence based on research and expert opinion and has been extensively peer reviewed by a panel of international experts. The formulary can be downloaded free of charge from the www.APPM.org.uk

To support the launch of the 2015 APPM Master Formulary the APPM is also undertaking its second international prescribing survey. This aims to identify priorities for ongoing work of the formulary group and should be completed by paediatric palliative care prescribers and those involved in advising on prescribing. Please assess the survey at

https://www.surveymonkey.com/s/APPM_prescribing_2015



**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

28th January 2015 **Human Factors in Healthcare**—A Balancing Act, Alder Hey Children's hospital sharon.goumas@alderhey.nhs.uk

29th January 2015 **One Day Advanced Course in Paediatric Palliative Care**, Bury Hospice Lynda.Brook@alderhey.nhs.uk

30th January 2015 **Update in Paediatric Palliative Care**, Bury Hospice Lynda.Brook@alderhey.nhs.uk

24th March 2015 **Advance Care Planning Level 2 Study Day**, ManCEL Centre, Salford Melanie.Lowe@cmft.nhs.uk

14th-15th April 2015, **Dying Matters for Living Children**, Together for Short Lives National Conference, Aston Conference Centre Birmingham, conference@togetherforshortlives.org.uk

28th-30th April 2015, **RCPCH Annual Conference**, Birmingham, www.rcpch.ac.uk

Northwest Paediatric Palliative Care Forum Sharon.Townsend@alderhey.nhs.uk

Dates for 2015 to be confirmed

Northwest Children's Palliative Care Network Lynda.Brook@alderhey.nhs.uk

Friday 6th March 2015 10:30-13:00, Francis House Hospice, Manchester

Friday 5th June 2015 10:30-13:00 Claire House

Friday 4th September 2015 10:30-13:00: Derian House (TBC)

Friday 4th December 2015 10:30-13:00. Greater Manchester venue TBC

Northwest DNA-CPR Implementation Group

Tuesday 27th January 2015, 10:00-12:00, NWTS Offices Warrington

Tuesday 24th April 2015, 10:00-12:00, NWTS Offices Warrington

Tuesday 10th July 2015, 10:00-12:00, NWTS Offices Warrington

Northwest Children's Palliative Care Research Group

Friday 13th February 2015, 10:30-13:00, Manchester University

Friday 22nd May 2015, 10:30-13:00 Manchester University

