



The Northern Neonatal Network
An Operational Delivery Network
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Northern Neonatal Network Project (Neonatal Comfort Care Plan) Final Report and recommendations

Executive summary

Following the subsequent launch in October 2013 of the new Network Neonatal Comfort Care Plan (NCCP) for palliative/end of life care as a pilot; a Network development opportunity arose for a successful applicant to undertake work as a Project Lead. In this instance to support/assist units with implementation of the NCCP in clinical practice with focus initially on the four Neonatal Intensive Care Units (NICUs) primarily because of likelihood of exposure to appropriate cases in the time scale period set. As well as the subsequent audit/assessment of its use and effectiveness to then submit recommendations for consideration of the Network Board following its completion on 31st March 2014.

Background

Stemming from a co-organised Paediatric Palliative Care Clinical Forum and Northern Neonatal Network "Challenges at the start of life" –A workshop on Thursday 22nd November 2012 at St. Oswald's Hospice, Newcastle; attended by staff from a wide and diverse range of professional backgrounds. A day which highlighted very different experiences from both parental and professional perspectives offering extremely helpful insights into the varying journeys encountered under such challenging and difficult circumstances, formed a subsequent steering group within the Network as the recommended multi-disciplinary and 'joined up' approach essential to define and identify best practice and how this can be applied within an appropriate pathway framework.

For current practice to benefit from the provision of extremely valuable information gained by attending such workshops it needs a method of distribution to the wider multi-disciplinary team (MDT) of individual units. With reference to improving palliative/end of life care to infants with life-limiting conditions it was important to acknowledge the current aspects of clinical practice deemed excellent, but also to recognise a significant need to pool the resources of MDT's to refine the package of care currently provided for these special babies and their families.

Health care professionals must acknowledge their role as advocates especially in these cases to work together to ensure the most appropriate and highest possible standards of care based on an individual needs are achieved, whilst limiting the variations that may occur depending on personal interpretation. Utilisation of a care pathway approach right across the Network, spectrum of providers and support groups has the potential if applied successfully to improve the care experience of palliative/end of life care babies/infants and their families. The role of the steering group co-ordinated by Martyn Boyd (Network Manager) was then to work through the process of drafting a suitable care pathway that clearly defined the options available, including when and how agencies that can provide care are involved.

Purpose

With the collaboration of the new Network NCCP for palliative/end of life care as a direct result of the dedication from Martyn Boyd, Yifan Liang (Consultant Paediatrician and Lead for the North East Paediatric Palliative Care Network) and other members of the steering group who contributed the feedback necessary to enable the revised document, which was subsequently launched as a pilot. On Thursday 10th October 2013 at the Network Clinical Forum at Allergate House a meeting attended by senior representatives from units within the Network, as well as steering group members who were introduced to a draft comprehensive NCCP designed to move this aspect of clinical care forward. The session kindly facilitated by Yifan Liang discussed the project as well as the hope that units will view the document not only as a valuable resource and tool to compliment best practice but also as a method of standardising approaches in care.

To offer assistance with the aspect of improving upon the 'joined up' approach as a particular aspect identified at the initial workshop, representatives from the three main hospices were also in attendance. Zoe's Place, Butterwick and St Oswald's all provide neonatal/paediatric palliative/end of life care and summarised their facilities, referral/admission criteria with the aim of highlighting how they can be included within the existing MDT. The overall aim to bring together the resources of both hospital and hospice settings to enable them to then work closer together for the improved provision of quality care and services to babies and their families at this most challenging and difficult time.

Following the NCCP pilot launch Dr Rob Tinnion (Higher Specialist Trainee, Neonatology) expressed a specific interest in this aspect of neonatal care with Yifan Liang and after consultation with Martyn Boyd and myself as Project Lead was welcomed on board as an extremely experienced Registrar well positioned within the Network, to assist not only with actual application of the NCCP but also the process of continuing to raise its profile in the clinical setting during the pilot.

Process

The group progress was informally centred on a series of regular face to face meetings as well as a predominate focus on email discussions to keep everyone up to date with developments, which are summarised chronologically below.

Thursday 12th December 2013

Attendees: Martyn Boyd, Yifan Liang, Rob Tinnion and Stacy Williams.

With the provision of details for the Nurse Managers/Clinical Leads by Martyn Boyd and having agreed with the timescale in mind as well as likelihood of suitable babies being identified to restrict the twelve units across the Network to the four NICUs, it was important that this initial contact assessed levels of awareness and any attempts to use the piloted NCCP since its launch in October. A 'champion' (or suitable clinical individual with a particular interest in this area) was sought from each unit who would be prepared to act as a local resource, particularly for the identification of suitable babies which could be where

necessary discussed with members of the project team. This was particularly slow to start with reference to obtaining responses but was felt to be partially hindered due to the imminent festive season.

Also to arrange visits to the 4 NICUs initially to discuss the use of the NCCP in clinical practice, emphasising the pilot period until 31st March 2014 and therefore the essential requirement of honest but constructive feedback. The overall aim being of the NCCP as a standardised consultant initiated 'parent held' document/resource designed to accommodate parallel planning that would move with the baby, whilst functioning alongside current documentation during this phase. Opportunities arose relatively quickly at RVI and JCUH shortly followed by UHNT for discussions, where Yifan Liang kindly agreed to deliver a background presentation to the NCCP with plenty of time allocated for peer interaction.

With a drafted 'working example' of the NCCP in use based on a suitable fictional case it was hoped would further support the awareness process as well as act as a point of reference in the Network Policies Folder beside a blank 'master copy'. Rob Tinnion and Yifan Liang agreed to help assure authenticity and accuracy before its distribution, although this aspect of the project took longer than anticipated and as a result was not made available as early as I would have preferred. This was however distributed with a 'Guidance for Use' (A) front sheet, full colour master copy (B) and for easy reference having found this beneficial personally the 'Summary' clarifying the Royal College of Paediatrics and Child Health (RCPCH) reasoning criteria (C) along with a request to acknowledge receipt.

The Northern Neonatal Network Newsletter Winter 2013 was used as an opportunity to enhance familiarity with the project and for reference this entry is included as appendix D.

Thursday 16th January 2014

Attendees: Martyn Boyd, Yifan Liang, Rib Tinnion and Stacy Williams.

With the identification of 'Champions' and unit teaching sessions completed it was becoming more apparent of the different workings of each of the four NICUs in the implementation of new documentation. Palliative/end of life care is by no means a new concept even in neonatal care but the application of a document in clinical practice with specific reference to this aspect was what this pilot was all about. This way both now and potentially in the future if successful, areas of best practice would be easily identifiable through a set format whilst units are working towards improving upon a standardised package of care available for babies/infants and their families.

Unfortunately a planned 'Taking Children's Palliative Care Forward In Cumbria' Paediatric Palliative Medicine Clinical Forum Study Day on Thursday 13th February 2014 was cancelled at which Martyn Boyd had asked myself to co-present a presentation, a missed opportunity for further raising awareness of the project within the Network. This is exactly what this pilot has been about, with an ongoing theme of increasing the NCCP's profile, encouraging awareness and during this process gaining an insight into the varying operational backgrounds of each of the four NICUs. As it was realised relatively well into the pilot period

through continuing to seek guidance from various professional groups and individuals considered to hold expert valuable information for the long term success of the project, just how complex a subject area palliative/end of life care is but in terms of 'getting it right' from the perspective of the NCCP document steps that must be taken.

Thursday 3rd February 2014

Attendees: Martyn Boyd, Yifan Liang, Rob Tinnion and Stacy Williams.

With the pilot completion date fast approaching the Spring 2014 newsletter provided the opportunity to inform the Network of current NCCP use in practice with a final request for careful consideration of any future possible suitable cases and provision of the essential constructive feedback necessary for future documentation amendments and recommendations (E).

This stage of the process further supported with the assistance of Rob Tinnion who kindly agreed to present 'Standardising Neonatal End of Life Care, The NCCP its Regional Use to Date' at the Network Case Review Meeting on 24th April 2014 with Yifan Liang and myself being unable to attend.

The essential aspect was then to obtain actual photocopies of the NCCP documents used with removal of patient identifiable markers as well as any associated feedback in order for the data to be collated and analysed in preparation for the collaboration of this report.

Wednesday 19th March 2014

Attendees: Martyn Boyd and Stacy Williams.

This was a face to face opportunity to discuss the project overall with the focus around the Northern Neonatal Network guidelines for the production of this report and the personal evaluation to be submitted alongside it.

Wednesday 16th April 2014

Attendees: Martyn Boyd, Yifan Liang, Rob Tinnion and Stacy Williams.

As a final group meeting this was about the long term success of the project and looking at how the information gained can be included into the current documentation or be highlighted as a recommendation within the report with reference as to how this particular package of care can continue to be improved upon.

For the future we are seeking to make the NCCP as user-friendly and comprehensive as possible, whilst covering all legal requirements including ongoing discussions with regional coroners, the local police force, the clinical records advisory committee and our fetal medicine colleagues. As well as utilising existing documents needed by other health care professionals within it to ensure it is a "one-stop" source of planning, implementation, assessment and recording. The project was designed to assess its usefulness in this aim and as a means of enabling better multidisciplinary care and onward referrals, such as babies with terminal or life-limiting conditions transitioning to paediatric inpatient or

community care, hospice or home. With a refined document tailored to accommodate the projects findings and recommendations rolled out across SCBUs and associated specialities in order to enable this process to occur smoothly in clinical practice.

Findings

In practice the NCCP was applied in four cases (W, X, Y and Z) across two of the NICUs where death was expected due to life limiting conditions, where complications of extreme prematurity meant continuing with intensive care management was viewed as futile and in one instance case 'X' where this document could have potentially been introduced antenatally had the tool been available in the setting at that time.

It was proven to enable a smooth transition to home from NICU in case 'W' allowing also for subsequent planning for death and beyond supported with enhanced MDT communication where the ongoing comfort of the child was clearly paramount. Also demonstrating its usefulness when intensive care is clearly identified as no longer being the viable option through the provision of a structured framework to maintain MDT working (X, Y and Z), whilst acting as a quick easy reference guide ensuring the maintenance of appropriate care with the allowance of variances according to clinical judgement. In these instances the document in its application assisted in the transition from withholding or escalation of treatment through to the actual withdrawal of treatment over varying periods of time. Demonstrating the NCCP has the versatility in clinical practice providing staff have the confidence to use it in a flexible manner. As it is suitable across the range of types of palliative/end of life care that can potentially be experienced in the care of babies/infants and their families.

Although it is not designed to replace clinical decisions at the end of life, in the long term it is meant to replace clinical notes with the exception of the pilot where it is appreciated some additional work was therefore created in its application. The Do Not Attempt Resuscitation Order (DNAR) was completed in all four cases and seen as an essential component for the understanding of all concerned in terms of how to proceed in the event of sudden life-threatening deterioration or cardio-respiratory arrest. By using only the relevant parts the NCCP has the flexibility to adapt itself for the tailored care of each individual baby and its family experiencing palliative/end of life care, and just as importantly in line with parallel planning this does include the option of discontinuing the care plan should it no longer be viewed as appropriate.

With the recognition and diagnosis of dying a complex process, irrespective of previous diagnosis or history and therefore uncertainty is an integral part of dying as sometimes patients live longer than expected or vice versa. It is worth mentioning that the concept was seen to be accepted by parents especially in cases 'Y and Z' as the document enforced an ongoing package of care that acknowledged life and not just the potential process of death and dying, providing families with a prompt to think about any important things they would like do with their baby with what time they may have left together. Whilst providing the

MDT with a tool to guide this process as a communicative aid between professionals protecting parents from any unnecessary repetition with their views and wishes clearly documented accordingly.

Recommendations

National guidance makes specific reference to communication, care planning, the presence of a MDT approach (ACT 2009 and BAPM 2010, RCPCH 2014) and auditing practice (BAPM 2010) all of which can be facilitated if a 'patient held' standardised care plan is applied regionally. A document that would replace existing medical/nursing notes that are not easily transferred between organisations, as well as one that is designed to assist the provision of high quality and integrated care to infants. As a framework for palliative/end of life care for MDT use across settings that can be used as a prompt for these difficult decisions with parents where appropriate as well as a tool to audit end of life care. The subsequent recommendations are made with the aim to enhance and improve the current NCCP that will in turn improve palliative/end of life care for babies and their families; a tool which I feel very strongly is the key to standardising best practice across the Network.

- The NCCP should be continued as a Network wide tool across all twelve units including both NICUs and SCBUs because it empowers even the inexperienced health care professional in palliative/end of life care to be able to guide the family through the process.
- A revised NCCP should be drafted to include amendments to the text with regards to Death Certification (p10) as suggested by Durham Constabulary to accommodate the full correct proceedings for the issue of a Medical Certificate when both cause of death is known and there are no suspicious or unusual circumstances, as well as when cause of death is not known and/or there are any suspicious or unusual circumstances.
- Also similarly with regards to Guidelines for Dealing with Potential Donors (p10) as all organ donations from children are subject to consent from the Coroner.
- To fully consider the documents ability to sustain its user friendly status when used solely for that period of care, particularly accounting for concerns surrounding added work load with the current two hourly assessment process in what may be an otherwise stable infant on NICU for example. Handing more responsibility to the health care professional with a guide for recommended assessment intervals based upon individual need and care setting.
- With the DNAR order used in all cases and deemed an essential aspect of the NCCP it will be crucial to monitor proceeding of the nationally revised document so that this work can be acknowledged and adhered to as appropriate.

- Work is ongoing with our regional coroners as currently their requirements of death notification differ throughout the Network, and the initial response is it is thought to be a 'good form', and with the possibility of presenting the NCCP at the Northern Coroner Society meeting in the near future further guidance may be accommodated in the subsequent revised document.
- With specific reference to case 'X' where concerns were expressed regarding the foetus viability ex-utero to continue liaising with our fetal medicine colleagues to enable future advanced MDT planning in conjunction with the family on how to proceed after delivery.
- The above would be further supported following any guidance received from the clinical records advisory committee in ensuring the correct procedures are adhered to in the implementation of new documentation within hospital trusts.
- As in the case 'W' advanced planning is essential in line with the unpredictable nature of death and therefore the possible long term support needed by families in the community, which would only be feasible with the inclusion of extensive resources provided by a combined hospital/hospice MDT.
- To enable the collection and analysis of more substantial data I would recommend a revised NCCP to be distributed Network-wide subject to a further review after a period of one year.
- Parents are a valuable external source of information that can be used to the greater benefit when seeking to improve palliative/end of life care and with careful consideration of the time lapse between the death of their child and any contact made; their views may also contribute to any further data analysis.

The consideration of these recommendations by the Network board is much appreciated and it is hoped that if accepted I will be in a position to continuing working with the project team in order to assist further with the actual revision of the NCCP document and its subsequent re-launch.

Mrs Stacy Louise Williams
 BSc (Hons) in Nursing-Child Branch, Registered Nurse-Child Branch
 Staff Nurse, Neonatal Unit, University Hospital Of North Tees
 Network Project Lead for Palliative/End of Life Care
 Northern Neonatal Comfort Care Plan (NCCP)
 June 2014

Appendices

Appendix (A)

Network Neonatal Comfort Care Plan (NCCP)

Guidance for Use

- Must be Consultant initiated
- Document must be printed in colour - Specifically for the Do Not Attempt Resuscitation Order (DNAR).
- To include regular reviews
- Consider parallel planning
- Parent held documentation

NB Pilot is until 31st March 2014 and during this period;
Photocopies of any documents used required for auditing purposes please forward to your Project Lead for palliative/end of life care below

Please use this period also to highlight within the NCCP areas of good practice as well as aspects that could have been improved upon for future practice.

Staff Nurse Stacy Williams (RN-Child)
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Appendix (B)

Neonatal Comfort Care Plan (working document)



Appendix (C)

Summary of the guidance from the RCPCH – “Withholding or withdrawing Life sustaining treatment ((2004)



**NCCPAppendix
C.doc**

Appendix (D)

Network Neonatal Comfort Care Plan (NCCP)

“Working Example”

A Fictional Case Study



**Appendix D part
1.pdf**



**NCCP Appendix D
part 2.pdf**

Appendix (E) - Network Newsletter article (Winter 2013)

Network Palliative/End of Life Care – Project Lead Stacy Williams (RVI)

“With the recent launch of the Network Neonatal Comfort Care Plan (NCCP) for palliative/end of life care, as Project Lead I am offering individual unit support/assistance with its implementation. This will include teaching staff how to apply the NCCP in clinical practice, including the provision of an accurate working 'example'. I believe the previous absence of forward/parallel planning within a structured format has potentially inhibited the execution of a joined up approach where effective communication is essential. It is important to acknowledge existing best practice whilst working towards a 'joined up' approach for the ongoing improvement in palliative/end of life care for babies. The subsequent audit/assessment at the end of the pilot period (31st March 2014) will consider its use and effectiveness in order to move forward with recommendations and any revised content.”

Appendix (F) - Network Newsletter article (Spring 2014)

Network Palliative / End of Life Care – Project Lead Stacy Williams (UHNT) *“To date as a team Yifan Liang, Rob Tinnion and I have overseen teaching sessions in three of the NNU's. This in turn has developed into successful implementation of the Network Neonatal Comfort Care Plan (NCCP) in two of the units across a breadth of cases, from a compassionate extubation of a sick extreme premature infant to the discharge of a baby with Trisomy 18 following a post-natal diagnosis who later died at home. From the data obtained to date as we near the end of the pilot period (31st March 2014) the subsequent audit/assessment should illustrate the documents versatility providing staff have the confidence to continue to apply it in the flexible manner for which it is intended. The inclusion of forward/parallel planning within a structured format can form the basis of a joined up approach where communication is essential, as we continue to strive to improve palliative/end of life care provided to babies and their families.*

Please continue to consider and use the NCCP as it is only through the constructive feedback provided that we can adapt the document to make it as clinically user friendly as possible!!”

References

ACT (2011) Valuing Short Lives. Basic symptom control in Paediatric Palliative Care. The Rainbow Children's Hospice Guidelines, Eighth Edition

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And

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