

Change management and neonatal palliative care

This article looks at the need for a training programme to equip neonatal health professionals with the skills, tools and techniques to improve the delivery of palliative care on the neonatal unit. It explores how this programme was carried out through study days and workshops using the Bliss Quality Improvement Programme.

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Every year more than 68,000 babies in England are admitted to neonatal care. These babies, who may be born extremely prematurely (under 26 weeks' gestation) or with extremely low birthweight, face a very challenging start to life. Although survival rates at 24 weeks' and above have risen over the past decade, the reality is that many of these babies do not survive.

Much work has been done over the past two decades to promote the need for services for children and young people with life limiting or life threatening conditions. However, neonatal palliative care has a number of unique facets, and differs from children's palliative care in a number of ways.

It often takes place in a busy intensive care environment, and professionals in neonatal services are increasingly challenged to provide care that is not dependent on technology and equipment. They also face the challenge of enabling families to spend time with their baby in a more home-like environment. Research indicates that as many as 98% of neonatal deaths occur in a hospital setting, with very few being babies supported to die at home or in a children's hospice.

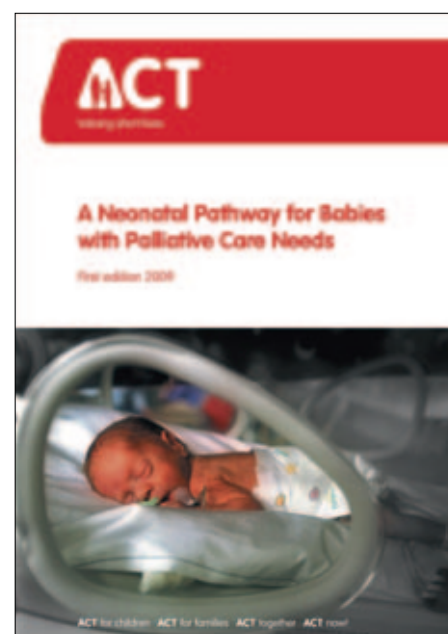


FIGURE 1 The ACT publication produced in collaboration with Bliss.

increased understanding of the basic principles of palliative care, with a focus on building awareness of the ACT pathway¹ and all other relevant recently published guidance. It also provided an opportunity to share examples of good practice. In order to ensure user participation was a central element of the study day, parents with relevant personal experiences were invited to provide their perspectives.

The quality improvement workshops taught the skills, tools and knowledge required to understand and implement change within a neonatal care setting, as well as offering the opportunity to begin to use the knowledge, guided by an experienced facilitator.

The ACT neonatal pathway (**FIGURE 1**), produced in collaboration with Bliss and published in November 2009, provides a framework to support healthcare

Training

Bliss in partnership with the General Medical Council (GMC), The Association for Children's Palliative care (ACT) and the Children's Hospices UK (CHUK) were able to provide an intensive training package consisting of regional study days across the UK, followed by a two-day quality improvement workshop to neonatal staff.

The study days were delivered by a team of experts in the practice of neonatal palliative care and helped to provide an

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palliative care; quality improvement; training; BQIP; care pathway

Key points

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1. An intensive training package to provide tools and techniques to effect change management is described.
2. The training enabled neonatal staff to plan to improve palliative care on their unit.

professionals to ensure that babies and their families receive the best possible care in these distressing circumstances. Guided by six sentinel standards, the ACT Neonatal Care Pathway recognises that babies and their families will make varied and individual journeys according to their own needs and circumstances. The pathway gives an excellent overview of the planning process as well as ensuring that family-centered care is at the heart of the whole process (FIGURE 2). The ACT pathway also aims to draw together neonatal service practitioners, maternity services, midwives and obstetricians as well as the children's and young people's palliative care sector to provide an integrated pathway as they care for babies at the end of their lives.

Study days

These one-day study days were offered free of charge to neonatal health professionals. The aims of the study days were to provide a clear understanding of the principles of palliative care, explore the full range of options available that is in line with current guidelines (GMC guidance on end of life care², BAPM standards of Palliative Care³, ACT neonatal pathway, CHUK hospice audit⁴) and to provide examples of good practice which can demonstrate the transition from hospital to community (home or hospice) care. It was helpful to be able to invite parents to share their experiences of palliative care, focusing on the good achievements and also discussing any challenges that they faced. The study days

helped to provide strategies for dealing with uncertainty, covering aspects such as conflict resolution and ethical issues around dying. The day was also for health professionals to share any examples of good practice that could be replicated in other sensitive situations. At each of the study days the local children's hospice was invited to share information about their hospice, and the facilities that they can offer for neonatal babies at the end of their life.

Bliss Quality Improvement Programme (BQIP)

The second phase of this project was an interactive two-day workshop. Bliss offered six capacity building programmes with a focus on palliative care to neonatal networks across England. Each programme comprised two workshop days, with a minimum of six teams of four to six people participating.

The BQIP training programme was piloted in 2009 in partnership with The Improvement Foundation. Evaluation by Bliss demonstrated it was a very effective vehicle for equipping networks with the tools, skills, knowledge and best practice to help neonatal staff identify and deliver improvements in practice. All participants rated the overall content of the programme as either excellent or good, and all felt that it had helped them be more confident at implementing changes in practice.

Although neonatal staff often have good ideas or have learned about good

practice through study days, they don't always know the best way to implement these changes when working on the frontline. Change management courses are more often aimed at managers. BQIP is designed to help frontline neonatal staff identify ideas for improvement and equip them with the skills to understand and implement change. It enables participants to implement change through innovation with limited resources. It has a minimal impact on the workload of participants, but is sufficiently detailed for them to develop their own skills and build on their own knowledge.

Outline of the workshop

All the teams that participated in the programme worked with a dedicated trainer, who helped them to creatively explore improvement options in areas of practice around palliative care. Each team was asked to develop an improvement project, with a clear goal for development or innovation which they wanted to achieve. This was focused around neonatal palliative care that was relevant to their specific local needs in their networks. The teams included a senior clinician who could ensure that the change could be introduced and that the unit would be receptive to and supportive of the proposed changes.

Participants also needed some protected time once back on the unit to develop or implement the improvement project within work hours. The teams reconvened at a second training day four to six weeks later, where they fed back on their progress and discussed their successes and the barriers they experienced.

As part of the training, each team shared their newly acquired tools and techniques with colleagues in their own unit as well as with colleagues in other units, within the network, helping others to achieve a similar change. Depending on the type of improvement, the projects could potentially lead to significant changes within both units and networks resulting in the adoption of new practices by large numbers of neonatal health professionals. To encourage this Bliss will be publishing all successful improvement projects online as part of their dissemination strategy.

Outcomes

All neonatal networks were offered these workshops and 30 units were able to



FIGURE 2 Pathway summary diagram, taken from ACT – A Neonatal Pathway for babies with palliative care needs⁵.

participate in small teams of four. There was a consistent attendance at all the workshops and all the teams were fully represented at both days.

The projects that the teams had decided to work on included the following:

- Reducing the time taken from point of referral to panel decision to a family being informed of a decision (referral from neonatal unit into a hospice setting for life limiting conditions)
- The discharge process from neonatal unit to home
- Empowering staff on a neonatal unit to actively use appropriate positions for sick babies (promoting developmental care)
- Improving communication when breaking bad news
- Implementing an up-to-date bereavement file for staff (staff knowing where to find things, eg how to get a death certificate)
- Improving communication between staff and parents by introducing a communication sheet for parents
- Identification of a baby with palliative care/end-of-life needs (improving consistency between senior clinicians)
- Care pathway for the fetal medicine unit
- Open attitude initiative for nursing staff (to pave the way for a care pathway)
- Individualised care package for families
- Staff education and training
- Parents to be offered the same tangible memories within the network
- Deciding which pathway a baby needs to follow
- Setting up a bereavement team
- Implementing an end-of-life plan
- Improving experience for families to feedback on neonatal palliative care.

Case study

Tameside General Hospital has a NICU which consists of three intensive care cots, six high dependency and ten special care cots. They have over 280 admissions a year and care is provided from 27 weeks' gestation onwards.

Their challenge was that although the need for well planned palliative care for neonates was infrequently required, the team agreed that their provision was not consistent. The support and care around the time of a baby's death was good, but there was no system in place to accommodate the care of a baby and its family away from the hospital setting.

The main driver for this project was not just the need to look at the palliative care

pathway but to improve the discharge process for all babies so that earlier, co-ordinated discharge could be facilitated.

They began by looking in detail at their discharge process overall for well babies. They convened a group of interested health professionals to share all their ideas and thoughts and to agree a baseline of where they felt they were currently at. They tackled the problem in small manageable chunks and identified people that would be proactive as well as individuals that may resist change. Using the tools and techniques provided at the workshops (PDSA cycles, Fishbone diagrams), they were able to identify the key stakeholders at different levels, the existing protocols and guidance, and evaluate the costs in terms of time, money and interest.

The stakeholders consisted of a wide range of professionals including neonatal consultants, NICU managers, children's community nursing team managers, health visitors, infant feeding coordinators, matrons, integrated services for children with additional needs, dieticians, speech and language team and commissioners. In particular the work with the Children's Community Nursing Team was a new way of working to meet the needs of commissioners and providers. This is unique in the Greater Manchester area as they were the first Children's Community Nursing Team to offer this service and it has been developed to reduce the bed occupancy days of neonatal babies.

They were able to put the following in place:

- An outreach service with the children's community team, for babies born less than 32 week's gestation or with additional needs
- Discharge checklists according to gestation and need
- Weekly discharge planning ward rounds
- Identification of a list of professionals involved in planning of discharges
- Ability to give more notice on intended discharge planning meetings
- Documentation to record events/discussions at discharge planning meetings
- Flow chart of responsibilities
- Weekly assessment of readiness for discharge for babies in special care
- Integrated pathway for discharge from NICU to outreach
- Home oxygen checklist.

An assessment to measure whether this

has been effective, has been put in place and will look at the number of babies referred to outreach, category of care (ex-preterm, home oxygen need, NG tube feeds), the amount of nursing time/number of visits given to each baby and the number of readmissions and the reasons for readmission. There were also plans to obtain feedback from families regarding the discharge process. As part of this assessment they also plan to determine the additional needs of families with palliative care issues and to utilise this existing process to formulate a palliative care pathway.

Conclusion

The feedback from each of the study days was found to be very relevant and helped to reinforce, support and develop an individual's clinical practice.

The BQIP programme has been a successful initiative for frontline healthcare professionals working on neonatal units. The tools and techniques that have been taught on these workshops have helped to guide the delegates through a systematic approach of looking at the current services they provide for babies at the end of life. They have been able to identify gaps within palliative care and put together plans for change and improvement. There is an acknowledgement that some units are limited by time, staff and financial resources as well as the concept of 'change' being difficult to embrace for some individuals. However, with this in mind, the units that participated in the workshops have definitely been able to work within their constraints to begin this process. They have found the workshops to be informative, educating and also an opportunity to work in their teams and to start planning. They have enjoyed being able to network across units and to share their knowledge and experiences throughout the workshops.

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References

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