Abstract
In 2004, a Framework for the Development of Integrated Multi-agency Care Pathways for Children with Life-Threatening and Life-Limiting Conditions, funded by the Department of Health, was developed by a working party. It included the Association for Children with Life-Threatening or Terminal Conditions and their Families, the Royal College of Nursing and the Royal College of Paediatrics and Child Health. This article will identify the need for this framework and its potential to transform the delivery of palliative care services to overcome present inequalities based on condition and geography that currently beset children with these conditions and their families. It will show how the three stages of the pathway (diagnosis or recognition, living with a condition, and end of life and bereavement) follow the patient’s journey and complement guidance set out in the Children’s National Service Framework (2004) for multi-agency assessments, protocols and standards to ensure high-quality coordinated care and services. It concludes with the need to evaluate the effectiveness of pathways that may develop from this initiative through audit and research.

Key words: Paediatric palliative care  ■  Care plans and planning

Coordinated palliative support can improve the quality of life of patients and their carers but, as the World Health Organization (WHO, 2004) has noted, knowledge about effective care rarely leads to widespread improvement without a deliberate effort being made to change practice. As they have identified, countries need to develop systematic ways of using knowledge to improve their health services. This includes; the development of clinical pathways, seeking user involvement and devising methods that encourage teams of professionals to work together to improve the quality of services provided. In particular,

‘Methods to coordinate palliative care between professionals working in different settings need to be tested in demonstration projects.’ (WHO, 2004 p29)

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Clinical, or care pathways, may be seen as the means of achieving this coordinated care. A number have been developed in adult palliative care, most notably the Liverpool Care of the Dying Pathway (Ellershaw and Wilkinson, 2003) but those for children have been slow to develop. In 2003 a working group of paediatricians, children’s nurses, educationalists, social workers and parents, under the direction of the Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT), the Royal College of Nursing (RCN) and the Royal College of Paediatrics and Child Health (RCPCH) was formed to aid the development of care pathways for children with palliative care needs and their families. The resultant framework (Elston, 2004) provides a template for those working with families to develop these locally and facilitate cooperation and coordination between professionals and services. This work is timely, for Government policy now is focused upon redesigning the way organizations deliver their services around the needs of patients to provide a whole systems approach to care, as well as joint commissioning of services between health, social care and other agencies (Welsh Assembly Government, 2004).

Paediatric palliative care: an inequitable service
At present there is no comprehensive provision of palliative care for children within the UK. As the recent House of Commons (2004) report acknowledged, whether children or their families receive the services they need is dependant upon their condition or geography. Children with malignant conditions (e.g. solid tumours and leukaemias) have access to dedicated centres of excellence which provide specialist medical and nursing services within hospitals and the community. In comparison, children with non-malignant conditions, whom it should be emphasized form the majority, are not so well served. Children with severe cerebral palsy may be totally dependant from birth, while children with other conditions become increasingly dependant because of progressive deterioration, for example in muscular dystrophy. For these children, needs may extend over several years as many survive to early adulthood placing a considerable burden of care upon their parents, who in most cases are their main carers.

Meeting the complex needs of the child, as well as those of their parents and other family members, depends upon multi-agency working between health services, social services, education and voluntary organizations, such as children’s hospices. However, seamless provision of care is
still problematic with many children and families receiving fragmented care. Respite, as an example, gives parents a much needed break from care and may be provided by health, social services or voluntary organizations. However, respite is in short supply and some never have the option to receive it. Research identifies that most children would prefer end-of-life care at home, but most die in hospital because of the lack of community-based palliative care teams for children. Sadly, it has also been suggested that end-of-life care within hospitals may be of a poor standard because of a lack of palliative care skills (House of Commons, 2004). Likewise, bereavement support for parents and siblings after the child’s death is not always provided and families may be heavily reliant upon voluntary agencies (Rolls et al, 2003).

On a positive note, the lives of many children and families have been enhanced by the care and support they have received from children’s hospices which provide respite and end-of-life care. At the time of writing there are 27 hospices with more planned (Association of Children’s Hospices, 2006). However, as charitable organizations the placement of hospices has not been planned strategically and while some parts of the UK are well served others are not. There is also inequity in regard to Government funding. England has the biggest concentration of hospices, but the NHS only contributes, on average, 6% of their expenditure through service level agreements. In Scotland – which only has two children’s hospices – the state contributes 25% (New Philanthropy Capital, 2004). Even so, the last few years have seen the setting up of eight specialist Diana Community Nursing teams across the UK, the appointment of a few medical consultants in paediatric palliative medicine (Hain, 2005), specialist courses at diploma and masters level, and a developing body of research (Emond and Eton, 2004).

Since 2002, new community-led paediatric palliative care services, funded by the Big Lottery (Big Lottery Fund, 2003), have been set up across the UK. The time is now ripe for a considered and rational use of these resources. The multi-agency framework, if applied in practice, has the potential to achieve this and ensure that a holistic continuum of care is provided for children and their families regardless of condition or geography.

The integrated multi-agency care pathway
The Framework identifies how care pathways, based on national guidelines and the latest available evidence, may be developed in practice (Campbell, 1998). It details essential steps of the patient journey and is divided into three stages:

 ■ Diagnosis or recognition of a life-threatening (LT) or life-limiting (LL) condition
 ■ Living with a life-threatening or life-limiting condition
 ■ End of life and bereavement

This is underpinned throughout by 5 sentinel standards to take account of what research has found to be the weakest points for families with regards to patterns of care (ACT, 2003).

Care pathways must be developed and owned by those who provide and receive the services therefore the framework is written in plain English to be accessible to professionals and non-professionals alike, including children wherever possible.

Stage 1. Diagnosis or recognition of an LT or LL condition
First standard

‘Every family should receive the disclosure of their child’s prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity. Information should be provided both for the child and family in a language that they can understand.’
Second standard

‘Every child and family diagnosed in a hospital setting should have an agreed transfer plan involving hospital, community services and the family, and should be provided with the resources they require before leaving hospital.’

Parents, understandably, are devastated by the diagnosis of an LT or LL condition in their child. Although recent research shows paediatricians and other medical experts are becoming better at breaking bad news, there is still room for improvement (Davies et al, 2003). The Framework, as set out in Figure 1, identifies good evidence-based practice. This includes parents being given the diagnosis in a quiet and private place with time to take this in and ask questions, the use of interpreters for families whose first language is not English, and backing up verbal information with written information, including as details of support groups.

Diagnosis may be given when the child is a hospital patient or in an outpatient department following investigations. Families are often discharged home without any back-up support in the community and parents may feel abandoned at a time when they most need the support of professionals. To prevent this, the Framework recommends an initial needs assessment meeting between key hospital staff, social services, the GP and the family. Issues, such as training in complex procedures for parents and professionals, special equipment, pharmacy supplies and transport, can then be discussed and agreed upon so that the needs of the child are met and the family feel supported upon their return home.

Stage 2. Living with an LT or LL condition

Third standard

‘Every family should receive a multi-agency assessment of their needs as soon as possible after diagnosis or recognition, and should have their needs reviewed at appropriate intervals.’

As shown in Figure 2, the needs of the child and family are many. The aim of a multi-agency assessment is for them to receive the right service, at the right time and in the right place. For most children with non-malignant conditions home will be the focus of care and families will need access and support from community-based services. For children with malignant conditions, hospital will play a major part with joint care between hospital and community outreach nursing teams. A major concern of parents is the relief of pain and other distressing symptoms such as seizures, swallowing difficulties and constipation in their child. Regular and ongoing assessment must be a priority if control is to be maintained. Quality of life for the child also includes having access to normal activities such as play, school and social contact with their peers.

The care plan, based on shared documentation, should provide details of statutory and voluntary agencies as well as contact details for named professionals. The keyworker’s role as coordinator is crucial to its success:

Fourth standard

‘Every child and family should have a multi-agency care plan agreed with them for the delivery of coordinated care and support to meet their individual needs. A keyworker to assist with this should be identified and agreed with the family.’

Many children, especially those with non-malignant conditions, are heavily dependent upon their parents, with mothers taking on the bulk of care. Respite, to give them a break from care, is vital to prevent physical, psychological and emotional exhaustion. This may include respite at home, within a respite centre or children’s hospice. Emergency respite should be available to cover a family crisis such as hospitalization of a parent.
The problems families face are greater where there is a single parent, social exclusion or for those whose first language is not English. The care plan should document this to ensure all families receive their entitlements and benefits as well as help with home adaptations or transport, e.g. motability (provision of adapted vehicles). More children with non-malignant conditions such as muscular dystrophy are surviving to adulthood (ACT, 2003). In the past disorders such as these were limited to childhood so it cannot be assumed that services or expertise have been developed in the adult sector (Beresford, 2004). For this reason, professionals and families are often reluctant to transfer the child from paediatric to adult services. The Framework recommends that transition planning begins when the child reaches 14 years to give the child, family, and paediatric and adult services time to manage this smoothly. In this respect, children under the age of 16 years who are deemed competent must be consulted about their needs and wishes. Likewise, permission should be sought from young people about inclusion of their family in the care plan as some may wish to live independently or have a partner included. The care plan should be reviewed on a continuing basis to reflect changing goals of care. Extra support will be needed during a family crisis, transition and when the child approaches the end-of-life stage.

Stage 3. End of life and bereavement

Fifth standard

‘Every child and family should be helped to decide on an end-of-life plan and should be provided with care and support to achieve this as closely as possible.’

Professionals must be honest and open with families when they recognize the child is approaching their end of life. Regardless of whether this takes place over hours, days or even months, families will need access to constant palliative care services. As shown in Figure 3, an end-of-life plan, agreed between the child, wherever possible, and family can help mitigate some of the their fears and anxieties during this difficult time and give them some control over the situation.

Parents will want to spend as much time as possible with their dying child and a balance has to be struck between their need for privacy and essential visits by professionals. For this reason, a small core team of professionals is likely to be appointed and the keyworker, acting as the family advocate, will liaise with them to ensure the family’s needs and wishes are documented and acted upon. A decision will have to be made in discussion with the family about withdrawal of non-essential drugs and other invasive interventions such as resuscitation or ventilatory support. The child or young person, if sufficiently competent, and family must be fully informed about these issues and feel their decisions are understood and respected by everyone.

Most families will prefer a home death while some may prefer hospital or a children’s hospice. Regardless of the environment of care, parents and other family members need time, space and privacy with their dying child (Davies, 2005). Parents dread their child suffering pain and need reassurance that this can be managed effectively. It is vital that the team has access to a paediatric palliative care specialist, paediatrician or specially trained GP so that pain and symptom control is exemplary. Quality of life for the child should also include pleasurable activities such as play, schoolwork and socializing with friends and family.

Planning together for death can be a positive experience for the child and family. The child may have special wishes or goals to achieve. For example, they may wish to provide a memory box for family and friends or have views on spiritual issues they need to share. However, some parents are unable to discuss death with their dying child and some children, protective of their parents, will not discuss this with them either. Someone, either on the team or known to them, must be available to support the child and family.

Figure 3. End of life and bereavement.
family sensitively in approaching the discussion of death and opening the possibility for the child or young person to make their own plans. The end of life plan should also document the family’s spiritual and cultural needs and their wishes after their child’s death, including their decision about organ donation or postmortem. Families need to feel they have control and choice in the care of their child’s body. For example, they may wish for their child’s body to remain at home before the funeral (Whittle and Cutts, 2002).

The keyworker needs to inform all professionals and services connected with the family following the child’s death. Practical advice, backed up with written information about official procedures and entitlements should also be given to the family. The needs of the family as a whole, including siblings and grandparents, must be considered at the time of death and bereavement services offered for as long as they need it (Dominica, 1997).

**Need to evaluate, audit and research pathways**

This article has given an overview of the multi-agency framework to show how it may be used to develop local pathways and provide a continuum of care for the child and family, from diagnosis through to end of life and bereavement. To evaluate effectiveness in practice, each pathway must document any ‘variance’, that is, any unexpected event in the child or family’s care. This may then be used to review, update and improve clinical and organizational practice so that changes may be incorporated swiftly into the pathway thus completing the audit cycle. The use of care pathways may highlight gaps in service provision locally and data collected may be useful in the planning of new services.

Adult palliative care pathways, such as the Liverpool Care Pathway, have been shown to improve symptom control in patients and support for relatives. The effectiveness of paediatric palliative care pathways, based on the ACT framework, must also be researched in keeping with the WHO recommendations already alluded to (WHO, 2004). User perspectives, in particular, need to be sought including those of children and young people. While parents can provide insights into their child’s care their perspectives are different and may not always reflect their actual needs or wishes. Action research, a qualitative approach which engages service users in the research design and process would seem the appropriate research tool for this and one which could provide new insights leading to the development of even more effective care pathways in the future.

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Association for children with Life-threatening or Terminal Conditions and their Families (2003) *Voices for change: current perception of services for children with palliative care needs and their families*, ACT, Bristol

**KEY POINTS**

- Locally developed care pathways have the potential to transform the delivery of palliative care services to children with life threatening and life limiting conditions.

- At present, inequalities based on condition and geography beset children with palliative care needs and their families.

- Care pathways, which mirror the patient’s journey, can aid multi-agency assessment and help ensure high-quality coordinated care and services.

- The effectiveness of care pathways must be evaluated through audit and research.