

Palliative care for disabled children and young people

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Abstract

Palliative care for disabled children and young people embraces holistic, high quality, evidence-based care, recognition and timely management of symptoms, recognition and discussion with the multidisciplinary team and with families about the possibility of dying and care and support through life, death and bereavement.

Systems are being piloted across the UK to collect data about who and where children and young people with palliative care needs are and to ensure robust funding mechanisms are established for provision of care in an equitable way.

Decision-making within a legal and ethical framework is paramount in this area of clinical practice, along with clinical networking within care pathways to ensure care delivered is of the highest standard.

Keywords best interests; child; clinical networks; decision-making; disability; disabled child; disabled young person; mental capacity act; palliative care

Definitions & numbers

Palliative care for children is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life to death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement. All disabled infants, children and young people require holistic, multidimensional, multidisciplinary and interagency care that accurately identifies and addresses their multifaceted needs. Thus the care of all disabled children and young people is concordant with the palliative care philosophy.

There are currently no robust data about how many disabled children and young people there are in the UK, nor how many children are at risk of early death or have palliative care needs. The UK's Chief Medical Officer in her special report 2013 focused on children and young people and dedicated a chapter to disabled children and young people: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/252659/33571_2901304_CMO_Chapter_9.pdf. Many of the

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recommendations called for better data collection if we are to reach the goal of delivering needs-based services that bring the best outcome opportunities in an equitable way for all.

Disabled children and young people and those with long-term conditions are at highest risk of death in childhood of all children and young people. Some deaths are preventable with high quality management. A proactive palliative approach can afford greater opportunities for involvement of the child and family in decision-making about care including at end of life and ensure the best possible symptom control.

Where data are available from routinely collected Hospital Episode Statistics, the numbers of children and young people with life-limiting or life-threatening conditions have been found to be double those of previous estimates and are increasing year on year. Life-limiting conditions are especially prevalent amongst ethnic minority groups and in families with increasing levels of deprivation. As Hospital Episode Statistics only capture data from those receiving correctly coded in-patient care the actual prevalence in the wider community is likely to be higher.

National policies, drivers and funding for paediatric palliative care Figure 1

Paediatric palliative care networks

The provision of children's and young people's palliative care via managed regional networks is being supported by Together for Short Lives (TfSL), the UK's leading charity supporting children with life-limiting and life-threatening conditions and all who care for them (formed by the merger of the 'Association for Children's Palliative Care' ('ACT') and 'Children's Hospices UK'). They define a palliative care network as: 'an interdisciplinary structured group representing providers and users of services over a defined geographical area, drawn together with the common aim of co-ordinating, strengthening and developing services for children and young people with life-limiting conditions'.

The East Midlands Children and Young People's Palliative Care Network (EMCYPPCN) for example, started in 2004 when members of the small children's palliative care teams from across the region began meeting at the local children's hospice to share knowledge, give mutual support and drive implementation of the 'ACT' Care Pathway. The Aiming High for Disabled Children regional board supported the network to develop governance arrangements and wider representation including commissioners. In 2010 the network supported local teams with 20 successful bids for the Department of Health £30 million funding, including development of a children's palliative care degree module at Nottingham university, a regional users and services mapping project, a directory of educational provision across the region, and several pilots including the rapid response respiratory physiotherapy service.

The network continues to serve an important role in bringing clinicians together for sharing knowledge and mutual support; the monitored work plan and short term working groups drive service developments and roll out good practice. User involvement has been problematic, but there are plans for a virtual reference group and links with the local Healthwatch.

The EMCYPPCN has now been adopted as a 'clinical advisory group' by the East Midlands Maternity and Children's Clinical Strategic Network. The latter will be supporting local commissioners to

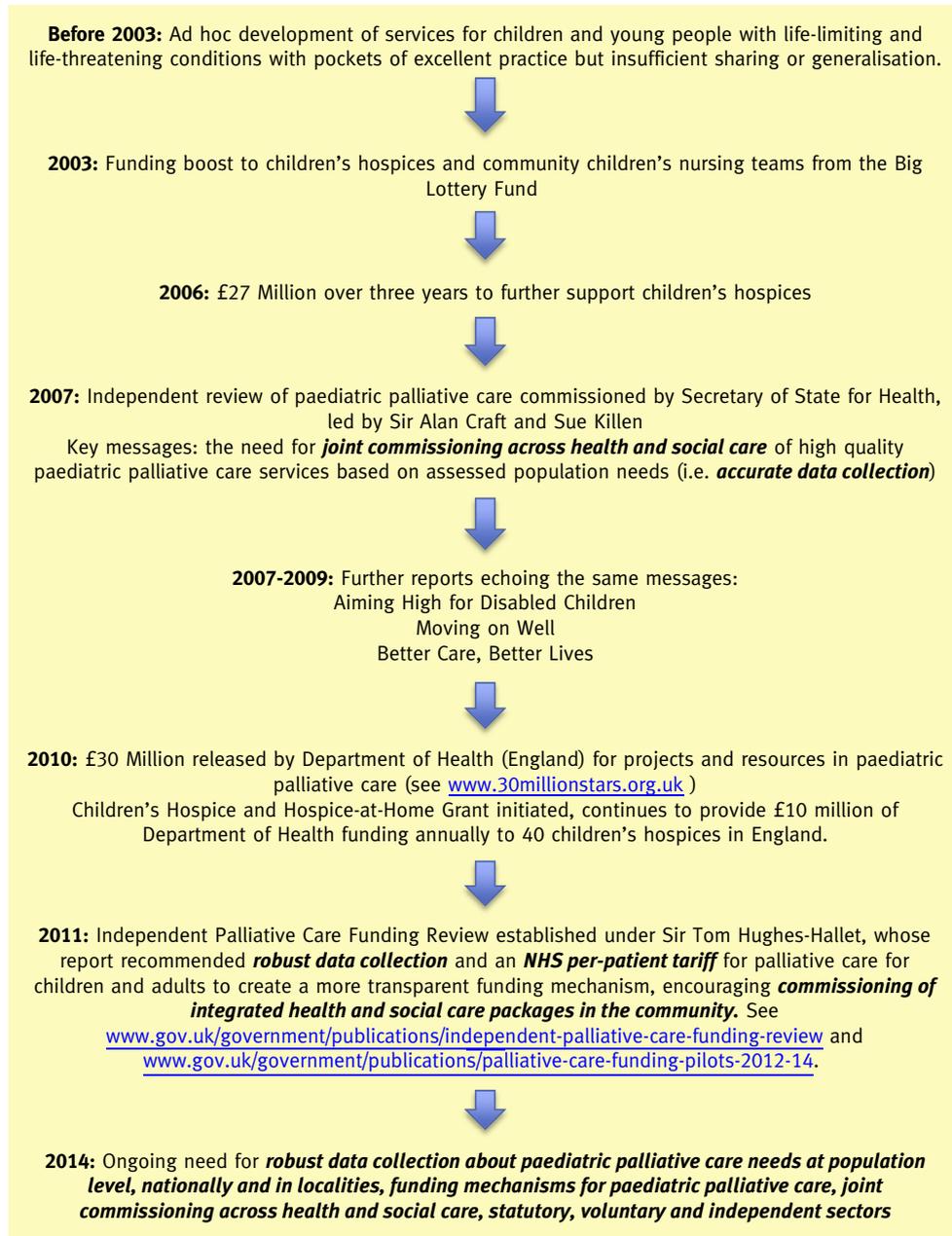


Figure 1 National policies and drivers for funding in paediatric palliative care.

collaborate with local authorities to commission 'core children's palliative care services' within the managed clinical network. These core services include children's community nursing teams, short breaks services, routine care by the children's hospice and other local community-based palliative care services.

A Guide for Clinical Commissioning Groups (CCGs) on commissioning children's palliative care in localities can be found at: http://www.togetherforshortlives.org.uk/about/our_policy_work/186_commissioning_children_s_palliative_care_in_the_new_nhs.

Information about the 16 current UK regional networks can be found at: http://www.togetherforshortlives.org.uk/professionals/service_planning/networks

The West Midlands Network tool kit is a particularly useful resource.

Specialist paediatric palliative care services

A service specification for specialist paediatric palliative care has been produced by NHS England for specialist commissioning: <http://www.england.nhs.uk/wp-content/uploads/2013/06/e03-paedi-med-pall.pdf>. However, despite initial proposals that each of the regional palliative care networks should have access to a specialist palliative care team for clinical, educational and strategic support there seem to be no immediate plans to extend the funding beyond the current small number of 'Highly Specialist Paediatric Palliative Care Centres'.

Transition to adult services

Transition arrangements for young people with palliative care needs, despite a plethora of frameworks and guidance, are highly variable and generally unsatisfactory although there are

Core care pathway for children with life-limiting and life-threatening conditions

1 The prognosis-sharing significant news	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 for the child and the family in a form that they can understand.
2 Transfer and liaison between hospital and community services	Every child and family diagnosed in the hospital setting should have an agreed transfer plan involving hospital and community services and the family and should be provided with the resources they require before leaving hospital.
3 Multidisciplinary assessment of needs	Every family should receive a child and family centred multidisciplinary and multi-agency assessment of their needs as soon as possible after diagnosis or recognition and should have their needs reviewed at appropriate intervals.
4 A child and family care plan	Every child and family should have a multidisciplinary and multi-agency care plan developed in partnership with them for the delivery of coordinated care to enhance family strengths and meet need. A multidisciplinary and multiagency team should be identified in agreement with the family and use key-working principles. This should involve all agencies supporting the child and family including children's community nursing team, allied health professionals, hospice, local acute and tertiary hospital services, education, social care and short break services.
5 An end of life care plan	Every child and family should be helped to decide on an end of life plan and should be provided with support to achieve this.
6 Bereavement support	Bereavement support should be provided along the care pathway and continue throughout the child's death and beyond.

Table 1

examples of good practice to aspire to. Together for Short Lives has launched a **Transitions Taskforce** that will share information and good practice nationally via an information hub and also work through Regional Action Groups to engage with adult services, commissioners and service users, mapping services across regions and identifying gaps in provision.

Care pathways approach

The care pathway approach to paediatric palliative care advocated by Craft and Killen is championed by Together for Short Lives. The 'Core Care Pathway', in its third edition, has been joined by 'Transition' and 'Neonatal' care pathways. There is no evidence that specific conditions produce typical pathway patterns, but all of the pathways are embedded in common principles of best practice, considering the best interests of the child or young person as paramount at all times (see more below about 'best interests'), embracing diversity and cultural issues, carefully considering issues of consent, capacity and confidentiality. Excellent communication is required at every step and care needs to be carefully planned and coordinated, taking account of uncertainties, with clear advice for the family about who they can contact round the clock if advice or support is needed (Table 1 and Box 1).

Case study with links to the core care pathway

James acquired Group B Streptococcal meningitis at 10 days of age, was seriously ill and almost died. He received neonatal intensive care and survived, but acquired panhypopituitarism for which he received hormone replacement treatment. The neonatologists spoke openly with his parents about the severity of James' illness and brain injury and the high probability of significant and complex disabilities. (Care pathway note 1: early communication about prognosis).

James' healthcare was transferred to the disability paediatrician, linking with the paediatrician with expertise in endocrinology and supported by the community children's nursing team. (Care pathway note 2: transfer and liaison between hospital and community services and multidisciplinary assessment of needs).

James continued to feed and thrive, but rarely woke up and was completely dependent on his parents for all of his care.

At four months of age he developed infantile spasms that were initially treatment resistant, requiring multiple anti-convulsants and high dose steroids to bring them under control. James had a clear emergency healthcare plan that supported full resuscitation and intensive care if required. (Care pathway note 3: a child and family care plan).

At five months, James was admitted to hospital for further investigation of his obtunded state. Treatment for his panhypopituitarism was found to be appropriate, his seizure control was adequate, but he still did not wake up. A magnetic resonance imaging (MRI) brain scan showed very extensive brain damage, with absence of central structures.

Both parents were seen together by the lead consultant, supported by the community children's nurse and the new information from the scan was explained, including the implications for risk of control centre failure and death. James' emergency healthcare plan was reviewed. The lead consultant explained that if cardiac arrest

occurred, this would likely be due to control centre failure and that cardiac resuscitation would be unlikely to be successful. The wording on the emergency healthcare plan was thus reviewed with his parents' informed consent, to allow a natural death when his time came. James' devoted parents were very private people and found coming into hospital with him very difficult. They indicated that they wanted all of his subsequent care to be at home. The lead consultant spoke and wrote to the Coroner, explaining the situation and sharing the new emergency healthcare plan, advising that he was expected to die and that his parents' wishes were for this to be at home. The Coroner endorsed the advance planning (Care pathway note 4: an end of life care plan).

At eleven months of age, James developed a bronchiolitic illness. His symptoms were managed with low dose oral morphine for his breathlessness and buccal midazolam for agitation from difficult coughing bouts. Doses were titrated against his symptoms. Oral feeding became difficult, so a nasogastric tube was passed for feeds and medicines. When breathing became increasingly difficult, medicines were delivered subcutaneously and continuously via a syringe driver. Care and support were provided by the lead consultant, community children's nurses and family GP. James survived this episode and as his symptoms subsided, he was changed back to oral feeding and his morphine and midazolam were weaned off. (Care pathway note 5: the management care plan was reviewed and changed with the family in the light of the change in the child's condition).

James enjoyed a further four months of quality time with his family, with trips to the countryside and seaside and some brief moments of awakening and smiles, which although few and far between were treasured by his family and captured on photographs to sustain their memories of the good times they shared as a family.

James then became suddenly unwell with a further respiratory tract infection. He received symptomatic support again, but deteriorated quickly and died peacefully at home with his family. The Coroner was notified and the death was managed as an 'expected death' under the Child Death Review procedures. Ongoing support through bereavement continued with the team, led by the GP. (Care pathway note 5: ongoing bereavement support).

Box 1

Recognising when death and dying may be possibilities

The care of children and young people with the most complex disabilities has changed over the last several decades, with increasing numbers dependent on technologies such as tubes for feeding, tracheostomies and various types of ventilation. Neonatal and paediatric intensive care are ever more advanced, improving the chances of survival for those with the most complex conditions compared to ten or twenty years ago. Increasing numbers of young people with complex, multiple disabilities are surviving childhood and needing continuing complex care packages through transition and in adult services. These children and young people may have a range of diagnoses, including progressive, neurodegenerative disorders, neuromuscular disorders, neuro-oncological conditions or conditions that have been previously described as

non-progressive such as cerebral palsies (Gross Motor Function Classification System levels IV and V), or chromosomal conditions. Individuals may become increasingly frail and vulnerable over time with the accumulation of secondary disabilities and complications, such as postural deformities, gastro-oesophageal reflux disease, constipation, feeding and swallowing difficulties, recurrent chest infections, epilepsies, spasticity and dystonia.

To date it has been rare to be able to cure or find treatments that modify life-limiting disabling conditions of childhood, but the new genetics and stem cell therapies are bringing exciting possibilities into clinical practice. Trials in progress include gene therapy for the Duchenne Muscular Dystrophies and enzyme replacement treatments for a number of inborn errors of metabolism. It is essential that all disabled children and young people are afforded opportunities for competent expert assessment to ensure that all have access to accurate diagnosis where possible, so as to have the opportunity to access condition-modifying treatment where this is available and accurate recognition and management of secondary disabilities and complications. Whilst keeping an eye on emerging technologies and options, it is equally important for clinicians to be mindful of the possibility of dying and death and to be open and honest with children, young people and their families to ensure that they have opportunities to be fully involved in decision-making at every step (Box 2).

Clinicians need to be prepared for the resilience and improved survival opportunities of children and young people who do not follow the journey predicted for their 'condition' in the textbooks, even in the face of very complex disabilities. It is never acceptable to assume that early death is inevitable and thus to neglect to address secondary disabilities or to manage all facets of a child or young person's predicament based on best available

'Red flags' that dying is a significant possibility in a disabled child or young person who is medically frail

- More time unwell than well
- Increased frequency of severe infections, taking longer to respond to treatment
- Increased frequency of admissions to hospital and/or to paediatric intensive care
- Increased feeding difficulties, with increased effort required to eat, drink or suckle and increased dysfunction of swallow
- Increased requirement for suction to clear upper airway due to decreased ability to clear own secretions
- Increased frequency of treatment-resistant seizures
- Increased agitation
- Changes in sleep, behaviour and personality
- Increase in pain, which may be non-specific and no cause may be identified despite thorough clinical assessment
- Control centre malfunction' as evidenced by intermittent or continuous temperature, respiratory and autonomic dysregulation with variations in temperature, breathing, skin colour and sweating that are not explained by medically identifiable causes such as sepsis

Box 2

evidence. Emphasis on maximising participation and quality of life must be overarching goals, embracing the best of evidence-based medicine along the way.

Talking about the possibility of dying and death

Many paediatricians will be familiar with the concept of Sudden Unexpected Death in Epilepsies (SUDEP) and may have some experience of discussing the risks with families. Recent evidence suggests that rather than the epilepsies themselves being the main factors for risk of death, it is rather the complexity of the individual's disabilities. Clinicians caring for those with complex disabilities have a responsibility to share information with children, young people and families about the risks of dying and

Ground rules for communicating with children, young people and their parents and carers about the possibility of dying and death

- Always actively listen to the child or young person, check what they know and understand at every step.
- Always actively listen to parents and carers, mindful that each may have a different view and have different needs in terms of how information is shared, understood and assimilated.
- Seek permission to share difficult information and check that the setting and circumstances are as supportive as can be.
- Give permission for others to be present as needed e.g. a grandparent, advocate or friend.
- Don't be afraid of silence. This is an important component of active communication, giving time for reflection and assimilation of information.
- Repeat important information and follow up in writing for the family and key involved professionals with consent.
- Consider the needs of brothers and sisters and other family members and offer support in communicating with the wider family.
- Involve the multidisciplinary team: the general practitioner, the therapists who know the child or young person best and the community children's nurses. It is essential for the team around the child to be aware, with consent, about the information that has been shared to avoid misunderstandings.
- Ensure prompt follow up, which may be with a different member of the team, to check understanding of what has been said and to offer support.
- Avoid absolutes. Trying to predict length of life and timing of events is fraught with difficulties although many families will push for this. Remain humble about what is known and what is not.
- Assure the individual and their family and carers of ongoing attention to symptoms and support.
- Be proactive in predicting symptoms and scenarios that might arise for the individual and ensure there is a robust care plan in place and that any medication that may be required is easily accessible and available should an emergency arise.
- Remember that it is discriminatory to put in place a 'Do not attempt cardiopulmonary resuscitation' order when an arrest is not an event that is anticipated in the individual. It is more likely for disabled children and young people to experience respiratory compromise or arrest than primary cardiac arrest and this should

be recognised in the documentation in the case notes and care plan, including the emergency healthcare plan.

- Discussing the possibility of sudden or 'unexpected death' does not mean that active treatment needs to stop. The child or young person can still receive full resuscitation and intensive care as required for as long as this is appropriate for them and has a chance of being successful. Supporting families through uncertainty, where there is a range of outcome possibilities, although tricky for clinicians is important for families, who value supportive honesty above all else.
- Being there alongside the child, young person and their parents and carers on their journey is as important as medicines in the overall therapeutic milieu and should not be undervalued.
- Be aware of the stages of the grieving process that families may encounter when they receive difficult news, including disbelief, anger, guilt, bargaining, searching, fighting, sadness and in time, acceptance.
- Be mindful of one's own feelings and emotions as a professional and do not be afraid to seek supervision and support. We are not always good at looking after ourselves as practitioners but we are no good to those we serve if we neglect to do so.

Box 3

death as it is only by being informed that the opportunity arises to be involved in decision-making, to express views and make choices about the care they would like to receive, including end of life care (Boxes 3 and 4).

Checklist if dying and death may be possibilities

- If death is a **possibility**, have you:
 - Exhausted all expert assessments and treatment options for the child or young person?
 - Offered and obtained a second opinion or further expert opinions?
 - Discussed the possibility of dying and death with the child, young person and their family?
 - If not, do this at the earliest opportunity to ensure inclusion in decision-making about end of life care.
 - Discussed plans fully with the child or young person's general practitioner?
 - Discussed with the local lead paediatrician for Child Death Reviews to ensure a robust plan in keeping with local arrangements?
- If death is **probable**, you **must** inform the Coroner. Coroners vary, but increasingly the default position is that they want to know in advance about all children and young people under 18 years of age where death is likely. Let them know about any emergency healthcare plan that states to allow a natural death (or equivalent) and all 'Do Not Attempt Cardio-Pulmonary Resuscitation' documentation.

- If death is **imminent**, have you:
 - Discussed with the child or young person and with their parents and carers their preferences about:
 - Place of care and place of death;
 - Who to call to say goodbye;
 - Spiritual needs (never be afraid to ask. Even those who do not practice a regular religion may welcome spiritual support at this time);
 - Choice of funeral home or undertaker. Advance warning is welcomed. Remember that many find the death of a child difficult too. Many will waive the fee for a child's funeral;
 - Taking pictures, hand and foot prints as memories;
 - Post mortem investigations.
 - Have you:
 - Planned ahead about who will be available to verify death e.g. general practitioner, specialist nurse, paediatrician, hospice doctor etc.
 - Discussed post mortem wishes with the family and with the Coroner.
- When death **occurs**:
 - Death must be verified as per regulatory requirements (medical/nursing).
 - Inform the Coroner about the fact of death.
 - Offer spiritual support.
 - Support family to link with the funeral care provider.
 - Inform the family of the local arrangements for registering the death.
 - Notify the local lead paediatrician for Child Death Reviews.
 - Ensure completion of the Death Certificate if the Coroner has agreed to this.
- See also http://www.togetherforshortlives.org.uk/professionals/resources/2779_end_of_life_planning_prompt_sheets_2012

Box 4**Decision-making in an ethical and legal framework**

All decisions must follow established ethical and legal frameworks, but there are two difficulties:

- Ethical concepts can vary considerably between clinicians and teams, and not every organisation has a clinical ethics advisory group to turn to for advice.
- Capacity and best interests are poorly defined in older children and young people. The consequence is that the decision of a 15-year-old is less well protected in law than that of a 16-year-old, whose decision is less well protected than an 18-year-old.

The concept of capacity and best interests is defined in those aged 16 years and over in the 2005 Mental Capacity Act (MCA). Although this legislation does not apply below 16 years, its principles and framework provide invaluable guidance:

Capacity: in anyone aged 16 years and over the MCA requires clinicians to assume the individual has capacity, unless they suspect an impairment or disturbance of mind or brain. Any informed individual with capacity for specific decisions aged 18 years and over has all the rights that the MCA affords and their

views are paramount, even if clinicians believe their decision is unwise or illogical. 16 and 17 year olds with capacity have the right to accept and refuse treatment, but cannot make a legally binding refusal of treatment in advance.

There should always be an assumption that the young person does have capacity until it has been demonstrated on clinical assessment that they do not. Individuals below 16 years who have capacity for specific decisions are 'Gillick competent' and can give consent for treatment. If there is suspicion of a disturbance or impairment of the mind or brain of the individual, capacity must be assessed by the clinician. Assessment of capacity is decision-specific: it is possible to have capacity for one decision (e.g. to have a blood test) but not a more complex decision (e.g. to undergo major surgery where there is a risk of death or significant morbidity). Assessing capacity is based on four tenants, all of which need to be positive:

Can the individual:

- Understand the information?
- Retain the information long enough to weigh it up?
- Weigh up the pros and cons?
- Communicate their decision?

It is really important to acknowledge that individuals with capacity aged 16 years and over have the right to make what others, including the clinical team, may consider to be 'bad decisions'. The MCA in England and Wales protects their right to do this.

Best interests: where an individual lacks capacity for a specific decision, the decision must be made in their best interests. Unfortunately this term is open to widely varying interpretation. The MCA provides a nine-point checklist for best interests which are a legal requirement in anyone aged 16 years and older. All carers, including the parents or legal guardians are subject to this checklist. Although it has no legal authority in those aged 15 years or under, it provides an invaluable set of prompts to ensure that all issues have been considered.

Q1. Is an Independent Mental Capacity Advocate (IMCA) needed? If an individual is aged 16 years or over and no one who knows the individual well or there is profound disagreement between those closest to the individual, you must consider instructing an IMCA. The IMCA will not make the best interests decision but ask the questions the individual would have asked if they had capacity. The IMCA will also provide a report on the process. Although an IMCA can be involved at short notice this must not delay urgent treatment.

Q2. Have you avoided making assumptions merely on the basis of the individual's age, appearance, condition or behaviour?

Q3. Have you identified all the things the individual would have taken into account when making the decision for them?

Q4. Have you considered if the individual is likely to have capacity at some date in the future and if the decision can be delayed until that time?

Q5. Have you done whatever is possible to permit and encourage the individual to take part in making the decision?

Q6. Where the decision relates to life sustaining treatment, have you ensured that the decision has not been motivated in any way, by a desire to bring about their death?

Q7. Has consideration been given to the least restrictive option for the individual?

Q8. Have you considered factors such as emotional bonds, family obligations that the individual would be likely to consider if they were making the decision?

Q9. Having considered all the relevant circumstances, what is the decision/action to be taken in the best interests of the individual?

If disagreement remains, taking the decision to a local clinical ethics advisory group can be invaluable but if this is not available, legal advice should be sought and the decision-making should be put before the court. Although a last resort, this should be seen by families as a constructive way of thoroughly exploring the issues and providing the child or young person and their parents with reassurance that the child's interests have been properly considered in the decision.

The principles and process cited above should equally underpin decision-making about infants and young children and support best practice in documentation of the process of decision-making. Best interests decision-making is a legislative requirement rather than a process that can rely solely on the personal opinion of an individual clinician (no matter how well-meaning).

One outcome of effective decision-making: emergency healthcare plans

This is an example of the outcome of a brief document that can facilitate communication in the event of a healthcare emergency that should follow the child or young person across all settings, from home to nursery or school to short break care and leisure activities. It may result from a discussion with the individual with capacity or be the result of a best interests meeting. Consequently it can be used to ensure the individual receives all treatment, not just to limit treatment. The plan should contain contact details for the child, their parents (stating who has parental responsibility) and key members of the multidisciplinary team including general practitioner, lead paediatrician, lead community children's nurse and any specialist teams or individuals pertinent to that individual. There should be a brief summary of the child's diagnoses and any active health concerns, their treatment or signpost to where up to date treatment details can be found. Predictable emergency scenarios should be documented (e.g. what a seizure looks like for this child, breathing difficulties, signs of shunt problems etc.) along with action to be taken by the layperson in the community through to the paramedics and emergency department clinicians. There should be a clear statement in the plan about what has been discussed and agreed with the child, young person and family about appropriate levels of intervention, which usually is a statement to protect their right to full resuscitation and intensive care if required. This is important to ensure that individuals in the community and clinicians do not make ill-informed

judgements based on the appearance or other characteristics of the individual that may lead to them receiving suboptimal care.

Further information about emergency healthcare plans and free training can be found at: www.bacdis.org.uk/training/training_resources.htm

A suite of decision support tools called "Deciding Right" have been developed in the north east of England, led by Dr Claud Regnard. These can be accessed at <http://www.cnne.org.uk/end-of-life-care—the-clinical-network/decidingright>.

Symptom control in palliative care for disabled children and young people

Principles of the best quality evidence-based healthcare must be applied at all times, ensuring that all facets of the child or young person's presentation have been correctly identified so that they may be appropriately addressed. This includes the correct elucidation wherever possible of the primary diagnosis or diagnoses as well as any secondary disabilities and complicating factors. Holistic assessment must always include specific enquiry about the presence (or not) of pain, as this has been evidenced to be a major determinant of participation in everyday activities and self-reported quality of life for children and young people with cerebral palsies. Where indicated, further expert opinions should be sought from paediatric disability and neurology clinicians as well as from experts in pain and other symptom management including paediatric palliative care specialists.

It is good practice to regularly review the treatment plan for the child or young person, discontinuing drugs and interventions that are no longer adding value. Anticipatory prescribing is empowering for families, ensuring that they have medications available across all settings and a clear care plan to guide when these should be given. Consider pain, nausea, vomiting, constipation, troublesome upper respiratory secretions, breathlessness and any other symptoms that may be predicted for that individual. Some families may prefer to telephone a member of the team first, to discuss the situation before giving a new medication. Ensuring families have access to the team at all times is essential; what this means in practice will vary by locality and may include the paediatrician, specialist nurse, GP, hospice, children's ward etc.

A Basic Symptom Control Guide in Paediatric Palliative Care, updated 2013, can be downloaded from: http://www.togetherforshortlives.org.uk/professionals/resources/2434_basic_symptom_control_in_paediatric_palliative_care_free_download

The Association for Paediatric Palliative Medicine Master Formulary (2012 Second edition) may be downloaded from: <http://www.appm.org.uk/10.html>

These should be used to augment expert advice obtained as a result of consultation via expert clinical networks.

Continuing care through death and bereavement

If death has been anticipated and the child or young person and their parents and carers fully involved in discussions and decision-making, it is to be hoped that the death will be as good as it can be. Questions will likely continue, lots of 'what if..'s and 'why?'s. It is important to answer all of the family's questions as honestly and straightforwardly as possible, always continuing to offer support. It does not help to be over-optimistic, nor over-pessimistic about likely length of life and it is always best to be

clear how difficult it is to predict exactly. There are many cases where death has seemed imminent only for the child to 'reboot' and to improve towards their former condition. Always be prepared to be surprised and always revisit decisions and the care plan to ensure it remains appropriate.

No matter how well prepared, the actuality of death is enormous for everyone. Make sure you prepare yourself and have your own support in place so that you can continue to be there for the family.

Bereavement support services vary by individual situation and locality. Involving the primary care team is essential for on going care for the family.

It is OK to go to the child or young person's funeral, especially if the family encourage this. It is OK to feel a sense of loss and to be sad. If we clinicians stop feeling, we limit our ability to genuinely care. Don't be afraid to seek support from colleagues if you begin to feel overwhelmed. It is good practice in any case to seek peer discussion and review of management overall when a child dies, with the team. What went well? What could have gone better? What could be done next time to improve?

Conclusion

The management of the medically frail child or young person with complex disability is an increasing workload for paediatricians. The care of this group can be regarded as palliative care. Some of these children and young people will need end of life care in childhood whilst others will need support in transition to adult services.

National reports and policies state that care should be provided as close to home as possible with a coordinated care pathway approach and a clearly identified lead paediatrician as well as general practitioner throughout the patient journey. Service development and funding arrangements have been highly variable across the UK. The challenge is to identify all children and young people needing the palliative care pathway and to put in place coordinated packages of care jointly funded by health and social care commissioners.

The palliative care funding pilots will identify national tariffs for children's palliative care and regional paediatric palliative care networks have the opportunity to support data collection by NHS number and to engage with commissioners through the Regional Maternity and Children's Clinical Strategic Networks. Meanwhile individual paediatricians can link with their local palliative care network, access all the excellent resources produced by Together for Short Lives and continue to provide high quality care to children, young people and their families. ◆

FURTHER READING

- 1 <http://www.togetherforshortlives.org.uk> (accessed 23 December 2013).
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Practice points

- All those delivering paediatric palliative care for disabled infants, children and young people should be competent in the assessment and management of all aspects of disability, or be actively working in partnership with paediatricians who are competent in disability as part of clinical networks, to ensure there are no missed opportunities for treatments or interventions that can improve participation and quality of life or length of life.
- Recognising when death may be a possibility and discussing this with families are important pre-requisites for involvement of the child/young person and their family in decision-making, including about end-of-life care.
- Decision-making about appropriate levels of intervention must always be within a legal and ethical framework.

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