



# Children and young people with complex medical needs

Intercollegiate Committee for Standards for Children and Young People in Emergency Care Settings

British Association of Paediatric Surgeons (BAPS)  
College of Emergency Medicine (CEM)  
JRCALC (Joint Royal Colleges Ambulance Liaison Committee)  
RCoA (Royal College of Anaesthetists)  
RCGP (Royal College of General Practitioners)  
RCN (Royal College of Nursing)  
RCPCH (Royal College of Paediatrics and Child Health)

## Introduction

Children and young people can have complex medical needs as a result of their underlying condition\*. Children who are born too early may have the long-term consequences of extreme prematurity; others have inherited conditions, chronic illness or sustain life changing injury. The spectrum of conditions includes cerebral palsy with significant disability, intractable epilepsy, autism, chromosomal and genetic conditions, chronic lung disease, complex metabolic disease, complicated cardiac disease, oncology or post-transplant.

There are children who are oxygen dependent, have tracheostomies and need regular suction. Some require enteral feeding, either nasogastric or by a gastrostomy or jejunostomy. Poly-pharmacy with unfamiliar medication is not unusual. New technologies such as vagal nerve stimulators, deep brain stimulators or intrathecal baclofen pumps are increasingly frequent. Palliative and end of life care plans may be in place.

Children with complex medical needs can present as an emergency with a complication of their condition or with childhood illness or injury. This presents a number of challenges in assessment and management.

## Case study

D is eight years old. As a result of a complication at delivery he has myoclonic epileptic encephalopathy and has severe learning difficulties and intractable epilepsy. He is hypotonic, unable to sit independently and uses a wheelchair for mobility. He is able to follow lights and responds to his parents' voices. D has had a Nissen fundoplication and bilateral femoral osteotomies. He has a tracheostomy and gastrostomy.

D has had frequent chest infections requiring intravenous antibiotics and has been admitted to hospital on many occasions, sometimes to a high-dependency area. D requires frequent suctioning and his family monitor his oxygen saturations.

D has seizures two or three times a day and has a seizure management plan in place for the administration of buccal midazolam when these are longer than usual. D's regular medications include three anticonvulsants, antispasmodics and prophylactic antibiotics. He is on a ketogenic diet.

D has been to the Emergency Department on 30 occasions in the last three years, often with prolonged seizures, chest infections or floppy episodes. His parents are usually present but sometimes he comes by ambulance with a carer from his school.

D's family are very caring and very anxious about him but are also reluctant for hospital admission. Intravenous cannulation can be difficult and sometimes his parents ask if this can be avoided.

## Issues to consider

### Emergency care plans

Check if the child has a documented individual emergency care plan. Parents and carers may bring a copy with them. Plans are especially useful for children with rare conditions or who require specific medical management. A plan empowers parents and carers and avoids the need for them to tell their story repeatedly. The plan is usually made by the lead clinician. If one is not in place, take the opportunity to prompt the lead clinician to prepare one for future reference. The plan needs to be up to date and shared widely, not only with the emergency care settings, but also with the wider professional team such as therapists, specialist nurses, schools, respite care, general practice and ambulance services.

### Contents of an emergency care plan

- Details of the child or young person and their family
- Contact information for key professionals and who can be contacted in an emergency
- Diagnoses and active health conditions
- Medications and signpost to further information
- Predictable scenarios and step-by-step guidance on actions to be taken
- Clear statement of what has been discussed and agreed about appropriate levels of intervention

### Who is with the child?

Children may present with their parents but can be accompanied by a carer or school staff member. Parental responsibility may need to be clarified. Identify the lead clinician who has overall responsibility for care. Be mindful that parents and carers may have had to repeat their complicated history on multiple occasions and over time they will become expert in their child's medical needs. While this can be helpful in determining what is usual for their child, they may not display the usual cues for parental anxiety. Do not assume that the child will be 'used' to clinical environments and acknowledge that this may be distressing. Issues of consent and capacity may be relevant in young people with complex medical needs over the age of 16 years.

### Privacy, dignity and communication

Children with complex medical needs require the same privacy and dignity as any other child. Providing a quiet private environment will help minimise distress for children with autism. Communication with children may be a challenge because of physical problems, understanding or behaviour. Always ask the parent or carer if there is anything specific you need to know about how the child communicates and whether the child has a particular way of displaying pain or distress.

### Systematic assessment and knowing what is usual for the child

Emergency assessment needs to be systematic as for any sick child. Consider whether this can be achieved safely and adequately for a child remaining in their wheelchair and balance this against any distress in moving the child. Some children have different anatomy and physiology and understanding the base line is important in evaluating the significance of clinical observations.

## Weight, drugs and nutrition

Children with long-term conditions may be underweight or overweight. This is important for accurate drug prescribing and may be forgotten in the transition to adult services. Children may require multiple and unfamiliar medications. There is a potential for drug interaction. Antibiotic resistance may be a problem. Children with disability or complex needs may have a poor nutritional status, unusual physiology and are at risk of rapid dehydration.

## Safeguarding

Children with complex medical needs deserve the same protection and standard of care as any other child. Special attention should be paid to the child's communication support needs. Avoid accepting a different or lower standard of parenting than would usually be acceptable because of the stress and difficulties of caring for children with complex medical needs. Children with limited or no mobility are likely to be osteopenic and may sustain fractures with minimal force and judgement is needed in making safeguarding decisions.

## Longer term follow up and care

Children with complex medical needs often have multiple appointments with numerous professionals. Emergency care may occur some distance from home. Ensure the lead clinician is aware of emergency attendances when there are changes or concerns, eg increased seizure frequency.

## End of life planning

Avoid jumping to conclusions about the appropriateness of full resuscitation and intensive care. Children towards the end of their lives may have a documented plan or 'wishes document' but can present unexpectedly in extremis when good decisions about starting or stopping resuscitation are needed, ensuring that the child if appropriate and parents and carers are involved in the decision making. Sometimes the child presents in a way which was not predictable and the cause may potentially be reversible.

## Standards

1. Triage systems need to take into account complexity and additional medical needs when prioritising care. These children and young people are frequent users of the healthcare system as a result of their condition. Allocating a higher priority will also allow the time that is often required to gather information, avoid unnecessary waiting, minimise distress and provide a better patient experience.
2. Good communication must include referring to the child's emergency care plan, listening to the child or young person and the parents or carers and finding out the preferred method of communication.
3. The needs of this group of children and young people must be considered in department design and the environment, eg appropriate toilets, weighing facilities, quiet areas, variable lighting and the use of distraction.
4. Where electronic alerts are available these must be used to signpost to relevant information such as emergency care plans or the requirement for an early senior assessment.
5. Information about the child or young person's attendance to an emergency care setting should be shared with the relevant professionals involved with them, including the lead clinician. Links should also be established with local specialist nurse and community children's nursing team to ensure effective follow-up care and support.

\* In this document the term children should be taken as meaning 'children and young people under the age of eighteen years'.

## Resources

'How do you want me to talk to you?' Supporting practitioner communication with children with exceptional healthcare needs, National managed Clinical Network for Children with Exceptional Healthcare Needs (NMCN CEN): [www.cen.scot.nhs.uk](http://www.cen.scot.nhs.uk)

Emergency healthcare plans, including video examples of how to have the difficult conversations that underpin the statement about agreed levels of intervention: [www.councilfordisabledchildren.org.uk/ehp](http://www.councilfordisabledchildren.org.uk/ehp)

Spotting the sick child with learning disability:

[www.councilfordisabledchildren.org.uk/resources/cdcs-resources/spotting-the-sick-child-learning-disability-module](http://www.councilfordisabledchildren.org.uk/resources/cdcs-resources/spotting-the-sick-child-learning-disability-module)

Treatment and care towards the end of life: good practice in decision making:

[www.gmc-uk.org/guidance/ethical\\_guidance/end\\_of\\_life\\_care.asp](http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp)

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## Review

This supplement will be reviewed in 2017 in line with the revision of the Standards for Children and Young People in Emergency Care (2012).

[www.rcpch.ac.uk/emergencycare](http://www.rcpch.ac.uk/emergencycare)