

Emergency Healthcare Plans

Professionals guidance



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Why recommend creating an Emergency Healthcare Plan?

When a child with complex healthcare needs becomes acutely unwell, prompt and appropriate action is essential. Emergency healthcare staff may not be familiar with the child's specific case or underlying condition. They require accurate background information to inform assessment. The child may not be able to indicate what is wrong and may not show the usually expected signs of illness. For parents and carers, the need to give an explanation of the child's condition, associated difficulties, and often lengthy medication list, can be very frustrating and stressful in an acute situation and may be perceived as delaying assessment of the immediate concerns.

Having a plan that has been agreed ahead of time can be empowering as well as saving time in conveying key information.

There may be situations when parents/carers are not immediately to hand, for instance when the child is at nursery or school, or with other family members, friends or short break carers. In these situations, having something written down can help to make sure that the right people are contacted in the event of an emergency and that the child gets the right and very best treatment at all times.

For these reasons it is recommended that children with complex healthcare needs should have an Emergency Healthcare Plan (EHP).

WHAT TO INCLUDE IN THE PLAN

A statement about resuscitation

The vast majority of EHPs should include a statement that protects the rights of the child to full care (i.e. assessment and management as per Advanced Paediatric Life Support (APLS) guidelines, including paediatric intensive care if needed). This prevents the situation where health workers unfamiliar with the child, and what they are like at their best, when well, may be at risk of making judgements based on poorly informed or unfounded assumptions about the impact of the child's condition or disability on their quality of life.

Suggested wording for the plan may be:

'For minor illness or injury, please consult [child's name]'s family doctor or the local primary care centre, as per usual arrangements. There can always be referral on to or discussion with the paediatric and/or specialist teams if need be.

'For more serious concerns about [child's name]'s health, please call 999 for a paramedic ambulance or take [child's name] without delay to the nearest emergency department for assessment and further management.'

'It has been agreed with [child's name]'s parents and all involved in their care that they should be assessed and managed as per APLS guidelines, including consideration for intensive care if required.'

Predicting scenarios

It is helpful for the lead clinician (usually the child's consultant paediatrician) to think about scenarios that may arise for an individual child and to prepare written guidance for parents and carers as to what steps to take should that scenario arise.

Examples of scenarios

Seizures

It is helpful to give brief descriptions of any attacks or seizures the child may have and for each attack type outline the steps that should be taken, e.g. basic first aid measures to maintain and protect the airway, removing any objects from around the child that they may hurt themselves on, when and how to give any emergency medication and which attack types need no treatment, when to call 999 for a paramedic ambulance, etc.

Blocked or infected ventriculo-peritoneal (VP) shunt

It is helpful for all children with VP shunts to have an EHP. This should include symptoms and signs to suggest shunt blockage or infection, e.g. reduced level of consciousness, unexplained fever, vomiting, headache, 'just not right', etc.

Episodes of decompensation

It is helpful for children with metabolic disorders and endocrinopathies to have an EHP. This should describe a typical episode suggesting decompensation together with the steps to follow, including any emergency treatment to give, when to call 999 for a paramedic ambulance, etc.

Impending respiratory failure

For those children at risk of impending respiratory failure, e.g. those with recurrent chest infections,

neuromuscular disorders, etc., it is helpful to include an 'alert' in the EHP about the possibility of respiratory failure and the need to be proactive in looking out for it, e.g. a prompt to check blood gases early.

Other scenarios

Any other scenario that may arise for the child, including any symptoms they may develop along with the management plan, should be added to the EHP.

Recognising when dying may be a possibility

Disabled children are at risk of sudden, unexpected death, the risk increasing with the complexity of the child's condition (CEMACH 2008). Clinicians need to communicate this compassionately to families and carers, not in order to frighten them, but to be honest about what may happen. Many families of individuals who have suddenly and unexpectedly died, for example in the context of the epilepsies (SUDEP), have expressed anger that they were never warned that this was a possibility. Discussions in the paediatric epilepsy clinic about the possibility of SUDEP are now part of good practice for those with the most active epilepsies, especially in the context of other disabilities.

Highlighting this risk does not mean that the child's treatment should be limited in any way: the child is still entitled to full care (APLS, intensive care if needed) and indeed may benefit from this and return to a good quality of life.

There is a small subgroup of children with complex healthcare needs, advanced neurodegenerative or

life limiting conditions where, in addition to the risk of sudden unexpected death, there are signs that the dying process may have begun. This is one of the most difficult clinical judgements that a doctor has to make and one of the hardest to start to talk about with families and carers. In order to start the conversation about the possibility of death, the clinician first needs to be aware that it might be a possibility. It is best practice to seek a second opinion when considering such matters and to seek the views of and information from the multi-disciplinary team who know the child best. Indicators that the child may be coming towards the end of life may include:

- more time spent unwell than well
- more susceptible to infections
- taking longer to recover from acute illnesses
- reduced ability to manage own secretions
- reduced ability to tolerate feeds
- symptoms that were previously well controlled, becoming less well controlled e.g. seizures, pain, etc.
- treatments that previously worked stop working effectively
- all possible medical treatments tried, with reducing benefit and increasingly challenging symptoms and signs
- signs of 'control centre malfunction', e.g. temperature dysregulation, changes in breathing rate or pattern, changes in heart rate
- new symptoms or signs emerge that cannot be medically explained
- agitation

- changes in sleep pattern, behaviour or personality
- reduced capacity for enjoyment of life, less smiles
- organ shut-down: gut, kidneys, skin, nervous system (may be signs of impending death).

None of the above is absolute and the diagnosis of dying is a clinical one: the recognition of a collection of signs and symptoms by an experienced clinician. *If in doubt, a second opinion should be sought.*

Introducing discussions about the possibility of dying, death and end of life care

Professionals are often reluctant to broach the subject of death. This is not surprising; it is emotionally upsetting and they are wary of giving parents pain. They may fear that parents will think they are giving up on their child or deciding when the child should die. Also, discussing the possibility or probability of someone dying always involves uncertainty. Professionals sometimes fear that admitting uncertainty may undermine confidence in them as a team or unnecessarily worry the family. They may choose to wait and see rather than share their expectations and be wrong. Discussing and managing uncertainty is a core facet of healthcare for children with the most complex healthcare needs, disabilities and life-limiting conditions.

Professional reluctance to broach the subject of dying and death may deny families the opportunity to prepare themselves and their child for death if they don't know it is even a possibility. It is

important to remember that no matter how obvious it is to you as a professional that a child's life is limited, parents may choose to block out that information unless a direct conversation takes place. Research shows that information and intellectual and emotional awareness of impending death are critical to minimising parental morbidity (Valdimarsdóttir and others, 2007).

A discussion about the possibility of dying and death should be initiated by the clinician once the clinician has recognised that dying and death are possibilities for the child, based on their holistic clinical assessment and taking into account the views of, and information from, the multi-disciplinary team who know the child best.

When considering where and how to have these discussions, the same principles as when sharing any difficult new information apply (Scope 2003), that is:

- with both parents present if possible
- in a place where they feel comfortable
- with privacy
- with respect for the child
- with enough time to explore their views.

The discussions should not be delayed and are most likely to take place during the course of either a routine clinic appointment or acute hospital admission. The decision about whether or not the child is present for the discussion should be a matter of clinical judgement at the time, respecting the family's preferences.

It is usually helpful to have another person present,

ideally the child's key worker, who will often be the community nurse, but an opportunity to have such a discussion should not be delayed if it arises.

Talking about their child's deterioration and possible death is of course difficult and distressing for parents. The paediatrician needs to be very sensitive and respectful. The discussions may be easier if the paediatrician already has a relationship with the child and family and can therefore speak with knowledge and experience. It would be usual for an EHP to already be in place, so the discussion could start off by suggesting a review of the existing plan. Prior knowledge of family dynamics is helpful, as well as an appreciation of the level of understanding of the situation from the perspectives of different family members, who may be in different states of mind and have different coping strategies. Do remember the child's siblings and make sure that they are included in the communication plan, even if this happens later.

As in any difficult communication it is essential to establish at the beginning of the discussions where the parents are in their own minds. Sometimes they will be ahead of the paediatrician in considering what is right for their child and wanting to limit unhelpful interventions. Sometimes they will have avoided thinking about it and want to continue without a clear plan in case planning will somehow hasten their child's deterioration.

The cultural, spiritual and religious views of the family must be taken into account and respected as the discussions progress. For those families for whom English is not their first language, a professional interpreter should be arranged to ensure accurate two-way communication.

‘There are a number of different paths that your child may follow. We need to make a plan together for each eventuality we can predict might happen, including the possibility that your child may die.’

The doctor should share what they know with the family and can acknowledge that they don’t have all the answers. Families appreciate honesty and prefer to be supported through uncertainty, knowing what the range of possibilities are, rather than being told what will happen with dogmatic certainty, only for something different to happen in practice.

Showing that you are honest, and caring and are coming on an uncertain journey with them builds a partnership between the healthcare team and the family.

Once the clinician has recognised that dying may be a possibility, sharing with the family the evidence that supports this conclusion can be helpful and all discussions – including the evidence upon which they are based – should be carefully documented.

Exploring levels of resuscitation:

It is important to talk through the details of resuscitation and intensive care treatment and what that would mean for an individual child. Decisions about withholding or withdrawing treatment should be made within an ethical framework and in the spirit of the guidance issued by the General Medical Council (GMC).

Generally, an EHP will already be in place and will have a clear statement supporting active resuscitation and intensive care as required. Therefore, for those children whose condition

deteriorates to the point where, in the clinician’s clinical judgement, dying and death are imminent possibilities, this statement about appropriate levels of care would need to be revisited and revised.

Possible phrases/scenarios to mention

- + We have evidence that the treatments we are using no longer seem to be working.
- + Your child is so very frail now (give evidence to support this statement) that intensive care treatment is unlikely to change the outcome and there would be a high probability that your child would die in the intensive care.
- + We are not giving up on your child. Rather, we are respecting their right to a dignified journey through dying and death. We will manage their symptoms always and be alongside you at every step of the way to answer your questions and support you. If you are stopping treatments, you need to emphasise what you are carrying on doing and that you are taking into account what gives the child comfort and pleasure.
- + Discussing the possibility of dying and death, even though painful, gives you the chance to make choices about where you would like your child to die and to think about what support you would like to have and any special wishes that need to be taken into account.

The doctor can sensitively suggest what they think would be the best plan of care, considering the positive and negative impact/consequences on the child’s health and well-being and listen to the

parents' responses.

When recording the plan it is important to keep the description of appropriate interventions positive, clear and practical.

Helpful forms of words to use in writing up the plan

◆ It has been discussed and agreed with [child's name]'s parents, taking into account [child's name]'s best interests, that in the event of [child's name]'s sudden deterioration or collapse, that [child's name] should be afforded dignity at all times, [child's name]'s symptoms should be actively managed, the family should be supported and [child's name] should be allowed a natural death when [his/her] time comes.

Where an EHP includes a statement to allow a natural death, the following should also be discussed and prepared:

- a DNA/CPR plan – if local policy requires it.
- a wishes document, specify more details about what the family wants in terms of care, place of care and any special arrangements.

How to reintroduce discussions when things change

Whilst with many families subsequent discussions may be easier, it is imperative not to assume that this will be the case. Some families may have blocked previous discussions from their minds and believe that because full resuscitation was

considered appropriate when their child's Emergency Healthcare Plan was first drawn up that this will always continue to be the case.

Focusing on recent changes in their child's condition, and the evidence that arises from the clinician's assessment, may help parents and carers process that change and acknowledge the need for a change in plan.

This is best done in the context of a medical review of the child. The doctor will be considering the child's clinical needs and all the current care plans. Again, it needs to be done with the same protected time and space as 'breaking the news'. Parent/carers may find it distressing if their child is deteriorating.

Helpful phrases:

- ◆ How do you think he/she has been since we last met?
- ◆ Things really don't seem to be going as well as we had all hoped... OR
- ◆ We really had hoped for... but this doesn't seem to be the way things are going.

It is particularly important that your language includes parents and carers, hence the use of the phrase 'all hoped' above. This can help to move them forward, including them in both the original assessment and inviting them also to review where their child is.

- ◆ We really ought to take another look at 'the plan' to see if we have covered as many possibilities as we can....

- ◆ What are you're concerns for the future?
- ◆ I think the has worsened.
- ◆ I find new problems (what?) when I examine him/her.
- ◆ I'm not sure that this bit of the plan is the right thing to do any more. What do you think? Perhaps we should do instead. That would be more appropriate/likely to work.

It is important to bear in mind that if you are telling parents/carers that a child is deteriorating they will ask you about you about time-scales.

It's usually very difficult to predict how long a child may live even when they are extremely frail. Avoid giving numbers but try to give some idea of how rapidly you expect things to progress.

You can say:

- ◆ There is a small chance that he or she will continue like this for many months or even years.
- ◆ It's more likely that things are going to worsen over the next days/weeks/months and we don't have any treatments which will be able to turn that around.

Managing uncertainty about time course

There is evidence to suggest that uncertainty surrounding the nature and course of a chronic condition increases family distress and that prolonged uncertainty that permeates a family's life can disrupt their ability to function effectively

(Cohen 1993a, 1993b; Sharkey 1995). However, research also indicates that discussing parental or carer concerns around the unpredictability of a child's life expectancy can help families learn how to manage the ambiguous nature of childhood chronic conditions (Dodgson et al 2000). Therefore, whilst clinicians cannot provide certainty where there is none, they can provide parents and carers with an outlet for them to voice their worst fears and their hopes and therefore to validate their experience (Garwick et al 2002).

It is of course critically important that healthcare professionals in no way add to the uncertainty by giving conflicting information and it is important that clinicians working with a family are agreed on and give consistent messages about the child's condition.

Emergency Healthcare Plans can therefore play a pivotal role in ameliorating, as far as is possible, the uncertainty of a chronic and unchangingly uncertain life course – acting as a record of what is known, providing an opportunity to discuss the uncertain and to plan for possible future scenarios. As indicated above, it is important to bear in mind that if you are telling parents/carers that a child is deteriorating they will ask you about you about time scales

Frequently asked questions and how to answer them

What happens if the emergency/duty team disregard/want to overrule our EHP?

Emergency staff will normally follow the Emergency Healthcare Plan as long as it is signed by the senior clinician. They want to give your child the best

possible care and having the plan helps them to know what has been agreed as the best plan of care by the clinical team who know your child's condition, together with yourselves. They would be unlikely to overrule that.

All health professionals have to do what is in the best interests of the child. The plan usually will give them the information they need to do that.

If something is not quite clear, emergency staff will try to get hold of your child's lead clinician by telephone. If there is not time to do that, they will always act to preserve life until they are certain that they are doing the right thing.

Whilst the final decision about the care that should be given rests with the senior clinician present at the time they should take into account the views of the individual and/or their family. If at any stage you don't agree with decisions being made you can ask for a second opinion. This, and sensitive discussions will usually resolve the situation.

In the rare cases when parents and clinicians still disagree, GMC guidance suggests that approaching the court can be a constructive way of thoroughly exploring the issues and providing reassurance for everyone concerned that the child's interests have been properly considered in the decision.

Who will have the final say in any medical decisions about when to stop active treatments?

Sometimes we can see that treatments to try to keep the child alive are not going to work or are causing too much suffering and that it is better for us to concentrate on treatments that will keep the child comfortable.

The doctor will always discuss what they think with the parents/carers and sometimes the child to explain why they think the treatment plan needs to change. They will take account of your views.

A doctor cannot carry on giving treatments that are not working, particularly if they have bad side effects or are painful.

What if I change my mind (about the contents of the plan) at the last minute?

It is worth bearing in mind that the best way to approach this question will be affected by the contents of the plan and whether or not what the parent is really asking is:

- a) What if I change my mind about not giving treatment? *or*
- b) What if I change my mind about giving treatment?

You can talk to the medical staff involved at the time of the emergency and talking through the situation and the best options will generally resolve matters.

Having a plan is not setting in stone a course of action or treatment. The benefit of having a plan is that you can think about what would be the best thing to do in a situation, when you're not going through the extreme stress involved in being in that situation – your child having a health crisis. Having a plan doesn't alter your right to change your mind. If the medical staff want to follow the treatment course set out in the plan you can still ask for a second opinion and still have all your usual rights to have your views as a parent taken into account.

In the very rare cases where, despite discussion,

parents and clinicians still disagree, then GMC guidance suggests that approaching the court can be a constructive way of thoroughly exploring the issues and providing reassurance for everyone concerned that the child's interests have been properly considered in the decision. The courts will consider what is in the child's best interests. Sometimes the emergency means that decisions have to be made very quickly. In those cases, emergency staff want to do the right thing. If there is any uncertainty in their minds about what is the best plan, they must (are legally obliged) do everything they can to try to keep your child alive and well. Then you can make a new plan once the emergency is over.

In transition: Who has the final say – parent, doctor or young person?

This section is reasonably complex and you may wish to refer to the section on capacity to consent, below

Ideally, we will all be able to work together to agree the best emergency care plan based on the doctor's medical knowledge, and the views of the young person supported by their parents.

The Emergency Healthcare Plan is the responsibility of the doctor who signs it and he or she has the final say. The doctor must always act in the best interests of the patient and take into account their views. How much say the young person has depends in part on their age but also on their capacity. Whatever their age, if the young person does not agree with the Emergency Healthcare Plan they can have a second opinion from a different doctor.

If they are under 16 and are 'Gillick competent' – which means that they have sufficient understanding and intelligence to be able to understand fully what is involved in the proposed intervention/treatment plan – then they are able to consent to but not refuse treatment.

If they are 16 or 17 – again a young person can consent to treatment but if they refuse treatment which is thought to be in their best interests that decision can be overridden by a court or in some instances a parent. If the young person does not have the mental capacity (as defined by the Mental Capacity Act) to make decisions about emergency care, the doctor will take into account the views of the family when making the EHP.

If the young person has capacity and is over the age of 18 years then the final decision making rests with them. Once they are 18 the young person can make an advanced care directive which is legally binding.

If the young person lacks capacity and is cared for by the local authority or a paid carer, then an Independent Mental Capacity Advocate (IMCA) should be appointed to support the decision-making process. The IMCA will collect views of all who know the individual the best, to formulate what their view would have been, had they the capacity to make the decision. In this case the decision-maker is the lead clinician.

With a young person with learning difficulties: Does my/our opinion carry any sway now my son/daughter is over 18

When the young person does not have the mental capacity to make decisions about emergency care the doctor will make a 'best interests decision' and

this must take into account your views as a parent. The doctor must consider the wider circumstances of the young person's life and will need information and opinions from you as parents/carers.

What will happen to my child's body if my child died in hospital could I take him/her home for a while or to the hospice?

It is usually possible to arrange to take your child's body home for a while or to the local hospice. The ward staff can help arrange this with you. If for any reason your child's death has been reported to the coroner then they would have the final say, but will try very hard to respect your wishes.

Will he/she have to have a post mortem (especially when there is no proven diagnosis?)

It is very unusual for a child to have to have a post mortem.

A post mortem would only be required if a coroner were appointed and there were concerns about the circumstances of the death.

If your child does not have a diagnosis despite lots of tests, health staff may offer you a post mortem for your child, but you don't have to have one.

Capacity to consent

This is a very complex area. The flow diagram on the next page captures the key elements and their implications for capacity to consent. However, this area is underpinned by a number of pieces of legislation, legal precedence and guidance. The key pieces of guidance are the Department of Health publications *The legal aspects of the care and treatment of children and young people with mental*

disorder and Reference guide to consent for examination or treatment.

The key pieces of legislation are the Mental Capacity Act 2005 and the Family Law Reform Act 1969.

The flow diagram and italicised paragraphs below are extracted from p202-3 of *Disabled Children: a legal handbook* (Legal Action Group, 2010) Steve Broach, Luke Clements and Janet Read, available at www.lag.org.uk or free to download from www.councilfordisabledchildren.org.uk.

**The law on consent to treatment, including treatment for mental disorder, for young people (aged 16–17 years) is governed by the Mental Capacity Act (MCA) 2005 and Family Law Reform Act (FLRA) 1969 s8. The MCA 2005 creates a rebuttable presumption that all individuals aged 16 or over have capacity to make decisions for themselves.*

For 16- to 17-year-olds, the MCA 2005 presumption of capacity to make decisions has to be considered in the context of FLRA 1969 s8. This provides that persons of this age can consent to any surgical, medical or dental treatment. The courts have, however, distinguished between the right to consent and the right to refuse – and held that in certain cases a court (or even a parent) can override a refusal by such a child (e.g. Re: R (A minor) (Wardship: Medical Treatment) (1992)). While it is questionable whether the case law based on FLRA 1969 s8 is still good law (preceding as it did the enactment of MCA 2005), it is nevertheless the case that the courts, in the exercise of their wardship powers, can override certain treatment refusal decisions of 16- and 17-year-olds even if the young person is 'Gillick competent'.



In case of disagreement about what is in the child best interests

It must be emphasised that the Emergency Healthcare Plan is the consultant paediatrician's medical care plan for that child. It must be a good plan of care which he or she can stand by as good practice. It is not just an endorsement of the parent's wishes. A plan can be quickly drawn up when both parents and paediatrician agree on the appropriate levels of intervention for the child.

Occasionally, the paediatrician and parents will not be able to agree the resuscitation section of the Emergency Healthcare Plan. In that case the paediatrician will write their views in the case notes in the usual way and the family will continue to state their views to the emergency medical teams on each emergency occasion.

Disagreements about what course of action would be in a child or young person's best interests can usually be resolved by: involving an independent advocate; seeking advice from a more experienced colleague; obtaining a second opinion; holding a case conference or ethics consultation; or using local mediation services. GMC guidance states that on the rare occasions when, after taking such steps, significant disagreement remains, clinicians should seek legal advice on applying to the appropriate court for an independent ruling.

Approaching the court should be seen as a constructive way of thoroughly exploring the issues and providing reassurance for the child and parents that the child's best interests have been properly considered in the decision.

It also needs to be borne in mind that it is not only between clinician and parent/carer that disagreement may arise. Sometimes there may be conflicting opinions amongst family members, this can be problematic where parents are separated or divorced. Children themselves may disagree with their parents. The clinician must ensure that all communication is managed to the best level possible, bringing in other experts as required to facilitate this.

Transition to adult services

Evidence of the benefits of planned transition is now emerging (Association for Children's Palliative Care (ACT) 2007) and a good transition can improve health-related quality of life for young people with complex health needs and disabilities.

Department of Health guidance on transition, *Transition: moving on well* (2008), makes it clear that well-planned, person-centred transition, sensitive to underlying needs, improves health, educational and social outcomes for young people. Good planning that puts the young person at the centre will prepare them and their family for the move to adulthood and transfer to adult healthcare.

The ACT transition care pathway provides an excellent model for children with life-limiting conditions, and may be adapted to serve a wider group of young people with complex healthcare needs. Royal College of Nursing guidance on *Adolescent Transition Care* provides an excellent model for approaching transition and includes a planning checklist and evidence record.

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EHP Core Principles and associated resources can be found at www.councilfordisabledchildren.org.uk/EHP

This short publication covers what an Emergency Healthcare Plan is and provides guidance on possible approaches to drawing one up. It is underpinned by online training available to access free at www.councilfordisabledchildren.org.uk.