

Emergency Health Care Plans for infants, children and young people with complex health care needs

CORE PURPOSE OF AN EMERGENCY HEALTH CARE PLAN:

To make communication easier in the event of a health care emergency for infants, children and young people with complex health care needs, so that they can have:

- The right treatment
- As promptly as possible
- With the right experts involved in their care

WHO IS AN EMERGENCY HEALTH CARE PLAN FOR?

Any infant, child or young person with complex health care needs (when the word 'child' is used from now on, it means all of these)

This may include those with:

- Complex disabilities
- Life limiting or life threatening conditions
- Endocrinological disorders, e.g. hypopituitarism, adrenal insufficiency etc.
- Ventriculoperitoneal shunts (including warning signs of raised intracranial pressure and indications for prompt imaging and neurosurgical referral)
- Metabolic disorders
- Cyclical vomiting
- Any condition or situation where having such a plan may help with communication in an health emergency

WHAT AN EMERGENCY HEALTH CARE PLAN SHOULD DO:

- Facilitate communication in the event of a health care emergency, from the first point of contact with the child, through to front-line health workers and on to specialist care
- Empower parents and carers, reducing the number of times they need to repeat key information
- Facilitate information sharing to inform accurate management, no matter which setting or whose care the child is in, e.g. at nursery, school, short breaks or with other carers or family members
- Help with triage in the emergency department, so that the child gets the right assessments and treatment in a timely way, with the right experts involved in their care

AN EMERGENCY HEALTH CARE PLAN:

- Is an advisory document - clinical judgement at the time of an emergency always takes precedence
- Is not a legal document, unlike an advance decision or advance directive, which are legally binding if made by a competent adult over 18 years of age
- If carefully prepared in partnership between families and professionals, should accurately reflect the child's best interests and therefore should be taken into account if a health care emergency arises, along with any new expressed views of the child or family at the time of the emergency

AN EMERGENCY HEALTH CARE PLAN SHOULD:

- be prepared after open and sensitive discussion between child, parents/carers and lead health professional, usually the consultant paediatrician
- keep the child's best interests and human rights as paramount at all times
- take account of the views of the multi-disciplinary team who know the child best
- always be drawn up within an ethical framework, taking account of statutory guidance, e.g. from the General Medical Council: 'Treatment and care towards the end of life: good practice in decision making', May 2010 and Royal College of Paediatrics and Child Health: 'Withholding and withdrawing life-sustaining treatment in children. A framework for practice', 2nd edition 2004
- be an agreed and recognisable format for documentation of resuscitation and levels of care decisions in the NHS Trusts where in use
- protect the equal rights to full care for those who 'appear' disabled, where front-line health workers unfamiliar with their care may otherwise make decisions based on inaccurate assumptions about their disabilities and the impact of these on their quality of life
- follow the child between all settings, e.g. home, school, short break care, leisure etc, so as to be always available should an emergency arise
- be made available to the local emergency and paediatric departments that the child is most likely to be taken to in the event of an emergency, both electronically and on paper
- be shared with, and recognised as a communication tool by, the local ambulance service, so that the plan is followed by all those in the care chain who are attending to the child
- be dated, so it is clear to all when the plan was agreed
- be dynamic and evolve with time, reflecting the child's current condition and best interests
- be easy to understand for parents, carers and professionals
- be brief, so as to be easily read in an emergency

AN EMERGENCY HEALTH CARE PLAN SHOULD CONTAIN:

- Basic contact details for the child, parents, key health professionals and any others who would need to be contacted in the event of a health care emergency;
- Key health information about the child, including any emergency scenarios that can be predicted in advance that might arise, e.g. seizures, breathing difficulties, vomiting, etc. with clear instructions about any emergency action to be taken by the parent/carer and front-line health workers, including any emergency treatment to be given and who to contact;
- Information about current treatment, including the weight (dated) used to calculate doses;
- Signposts or links to further information about the child's diagnosis, care or management; this can be especially useful for rare/unusual conditions, e.g. the British Inherited Metabolic Disease Group produce up to date emergency guidance for a range of conditions, accessible at www.bimdg.org.uk/protocols/topics.asp;
- A clear statement about what has been discussed with parents/carers and agreed about appropriate levels of care, written in a way that is clear for all front line health workers to understand e.g. follow Advanced Paediatric Life Support (APLS) guidance, Basic Life Support (BLS) or allow a natural death:
 - For most of those with complex health care needs the agreed statement should be to assess and manage as per APLS guidelines at all times, including intensive care if needed; this statement protects the rights of those who 'appear' disabled to full care;
 - In very few cases, where there is a known life limiting or life threatening condition or extreme frailty regardless of cause, but where death is not thought to be immediately imminent, the agreed statement may be to initiate basic life support, but call the most senior doctor available to discuss appropriate levels of care in the circumstances;
 - Where death is believed to be inevitable, usually within days or hours and life saving or prolonging measures would be likely to cause undue suffering and be unethical, the agreed statement may be to address symptoms at all times, treat with dignity and respect, support the family always and allow a natural death when the time comes.

IN CASE OF DISAGREEMENT ABOUT WHAT IS IN THE CHILD'S BEST INTERESTS

- Sensitive discussion with the most senior clinician available, preferably the one who knows the child and family the best, should lead to resolution in most cases
- Where agreement cannot be reached, prompt legal advice should be sought and decisions should be put before the courts if need be

Parents' experiences of Emergency Health Care Plans

Kay Green, mother of Matthew:

As the parent of a child who was undiagnosed and had very complex needs the Emergency Health Care Plan became a very useful tool when dealing with health, social care and educational professionals. It was readily accepted at Sunderland Royal Hospital when Matthew was admitted to A&E and saved a lot of the usual and very repetitive questioning from Junior Doctors about his medication, cognitive function, usual health and what was 'normal for Matthew' etc.. It was also accepted by our GP as a means of keeping up to date with Matthew's current needs as we didn't access GP services very often apart from requesting repeat prescriptions. As Matthew was educated outside of the City boundary it became a recognised and accepted way of the school nurse keeping up to date with

changes in medication and treatment plans as it went everywhere with him and everyone knew where the Plan was and that it was always current. Matthew spent equal time during the week between his Dad's house and mine so the contact information on the Plan for us as parents was vitally important, we were reassured that people had the most up to date contact details for us and that they knew that either of us could be contacted at any time if something went wrong whether he was in respite, at school or out with other people, everyone knew that the Plan was in his Communication Bag on the back of his wheelchair and that he always had it with him. The Plan was often seen as a safety net by other people too should anything happen so that they didn't have to worry about not knowing what his current medication was the Plan would be handed over to medical staff and treatment could be started before one of us got to the hospital. During the last year of Matthew's life he was very ill and constantly readmitted to hospitals in Newcastle where the medical staff got to know him very well. However, at the start of his illness when the staff

didn't know him the Plan came into its own as we found that while we were saying exactly the same as the information that was detailed in the Plan it was more 'valid' because it had a fellow professional's signature on it. The Plan backed up what we were telling the staff, thus eventually building up trust between all parties. Also it gave contact information for his Neurodisability Paediatrician which enabled the ward staff to contact her more easily should any queries arise that we, as parents, were unable to answer. This in turn led to an increased information flow around Matthew and better and more joined up treatment during his illness. During the final weeks of Matthew's life the Plan became a more substantial source of reassurance to our family specifically around our wishes for non resuscitation should he take ill while we were out of the house or he was away from us. These wishes were clearly stated and agreed with his Neurodisability Paediatrician should he be admitted to hospital, the Plan also stated that we felt that if possible for his dignity and for our own reasons we would like him to die at home in his familiar

surroundings which is what happened. Discussion around the last Plan also enabled us as a family to come to terms with what was an inevitable outcome for Matthew, we were able to start planning what we would do with the short time

we had left with him and to discuss it more easily with other people. The wording of the Plan (whilst a shock to read the first time as the situation suddenly became more real to us seeing it in print) also reassured us that our wishes were acceptable

and viable, that we weren't asking for something that was completely out of our control. We felt that it 'authorised' us to let Matthew have a peaceful, pain free and dignified death at home surrounded by the people who loved him.

Toni Mathieson, mother of Lucy:

Lucy was diagnosed with the rare and complex condition Niemann-Pick Type C disease in 2003, when she was just three months old. After receiving this devastating diagnosis, the family were thrown into a never ending round of appointments with the long list of professionals that would now become part of their lives. They found themselves having to tell their story time and time again, in some cases they found that they knew more about the condition than the professional - this became extremely difficult and upsetting. The family found themselves having to continually pester the appropriate authorities in order to convey Lucy's need for essential care, equipment and services to assist her in daily living. Resident in the

Sunderland area, Lucy was transferred to the care of her local Consultant in Paediatric Neurodisability at two years of age. The family were given the opportunity to create an Emergency Health Care Plan for their daughter and life transformed - visits to the A & E department became easier, communication between the many professional disciplines involved in Lucy's care improved greatly and Lucy began to benefit from individual care and support that was delivered as her needs presented (not six months too late!). The personal experience of Lucy's mother, who is also Executive Director of the Niemann Pick Disease Group (UK), has proved to be extremely positive in relation to families in other parts of England. The provision of Emergency Health



Care Plans contributed greatly to this experience, encouraging multi-disciplinary communication between professionals of all levels and ensuring that her daughter, Lucy, received optimum and accurate care during her short life. In this family's experience – having just four years with their daughter – it was very important to address complex and sensitive issues in a timely and appropriate fashion. The Plan ensured that Lucy's care was seamless and that all professionals – even those not involved on a regular basis were aware of and respected the needs and wishes of Lucy and her family.



Professionals' experiences of Emergency Health Care Plans

PAEDIATRIC EMERGENCY DEPARTMENT PERSPECTIVE Dr Darren Bresnen, Consultant Paediatrician, Sunderland

"Emergency Health Care Plans provide an excellent, rapid and concise way to summarise a child's condition or working diagnosis, and a systematic approach to emergency management and early hospital care for children. Moreover, they can suggest 'special tests' to be performed in times of acute decompensation, which have carefully been planned in advance. They may even provide clinicians with the confidence of extra added information to make a more informed assessment of an appropriate route of 'disposal', whether that be admission or indeed discharge, which may be preferred by care-givers, from the Emergency Department. Contact details for key professionals in times of crises are also a great asset to every plan."

GENERAL PAEDIATRIC PERSPECTIVE Dr Neil Hopper, Consultant Paediatrician with an interest in endocrinology, Sunderland:

"I have found Emergency Health Care Plans most useful for children with adrenal failure. These children can deteriorate quickly unless given appropriate treatment. Having a written plan in advance gives front line staff the power to intervene early, for example with IV steroids, in situations they may never have encountered before, with confidence, without delay. The feedback from parents has been really good, there is nothing more frustrating when your child is ill than having to explain the situation to a doctor or nurse who may not be familiar with the condition, or its management. They are very useful when children go away from their usual area of care, for example on holiday. They are now a standard part of my practice for any child who has a complex condition which may rapidly deteriorate'.

NEONATAL PERSPECTIVE Dr Lorna Gillespie, Consultant Neonatologist, Sunderland:

"From a neonatal perspective my experience with emergency health care plans has been very positive. Emergency health care plans give me reassurance that the parents have written information regarding how to seek help and who to seek help from. Also when the baby was on the neonatal unit, the baby and the parents were in an environment where all health professionals knew the child's medical background. Once discharged home, hospital review will usually be in a different setting to the neonatal unit, encountering different health professionals who do not know the medical background. In my view the emergency health care plan aids with that transition process from neonatal to paediatric care and can be quickly read by other health professionals in order to administer appropriate emergency care'.

COMMUNITY CHILDREN'S NURSING PERSPECTIVE Trish Maltby, Jill McDermott and Christine Hopkinson, Specialist Community Children's Nurses, Sunderland:

"As a group of community children's nurse's who care for children with very complex health problems and children with life limiting conditions we have found Emergency health care plans very useful. It equips the parents with written information they can present, for whatever situation may arise with regard to their child's illness or condition whether at hospital, school, respite or if on holiday. It enables us to have open and honest conversations with the child and family once levels of care have been planned especially those within palliative care. Parents report to us that they are invaluable when their child is unwell or if other professionals become involved in their care'.

Where to find more information

Support for clinicians in decision-making about appropriate levels of care:

'Treatment and care towards the end of life: good practice in decision making' GMC May 2010 www.gmc-uk.org/guidance/ethical_guidance/6858.asp
www.gmc-uk.org/guidance/ethical_guidance/children_guidance_index.asp
Withholding and withdrawing life-sustaining treatment in children. A framework for practice (2nd edition 2004 – currently under review). Royal College of Paediatrics and Child Health www.rcpch.ac.uk/Publications/Publications-list-by-title#W
NHS Toolkit for high quality neonatal services (2009) (www.dh.gov.uk)
"Palliative care (supportive and end of life care)" British Association for Perinatal Medicine (BAPM) www.bapm.org/media/documents/P%20alliative%20Care%20Report%20final%20Aug10.pdf

Advocacy for children, young people and parents:

Advocating for children (January 2009) Royal College of Paediatrics and Child Health (www.rcpch.ac.uk)
Patient Advice and Liaison services (England) provide support, advice and mediation for children, parents and other carers.
Community Health Councils (Wales) www.communityhealthcouncils.org.uk
Partners in Advocacy (Scotland) www.partnersinadvocacy.org.uk
Children's Advocacy services (Northern Ireland) www.niccy.org
Children First for Health: an NHS online resource to help children and parents share their experiences and get information www.childrenfirst.nhs.uk
Triangle is an independent organisation that supports children and young people to express their views about the things that matter to them. They recognise that some children may need best interests advocacy at times in their lives and they can provide this, especially where children are very young or have significant cognitive impairments. www.triangle.org.uk

Parent support organisations that produce leaflets and give telephone advice:

Bliss www.bliss.org.uk (leaflet: 'Making critical decisions for your baby')
Tiny Life www.tinylife.org.uk
Cerebra www.cerebra.org.uk
Contact a Family www.cafamily.org.uk

Organisations with further information for parents, carers and professionals, including suggested templates for emergency health care plans:

Council for Disabled Children www.ncb.org.uk/cdc
Royal College of Paediatrics and Child Health www.rcpch.ac.uk
Association for Children's Palliative Care (ACT) www.act.org.uk

Other references

User views of Emergency Health Care Plans for disabled children and young people. Jones N, Fetherston A, Horridge K. *Dev Med Child Neurol* 2009;51(7):570-571
Assessment and investigation of the child with disordered development. Horridge KA. *Arch Dis Child Educ Pract Ed* published online October 6, 2010 doi:10.1136/adc.2009.182436
Personal resuscitation plans and end of life planning for children with disability and life-limiting/life-threatening conditions. Wolff A, Browne J and Whitehouse WP. *Arch Dis Child Educ Pract Ed* published online October 13, 2010 doi: 10.1136/adc.2010.185272
Department of Health. (2007) National Service Framework for Children, Young People and Maternity Services: Children and Young People who are Ill: Standard 6. Assessment of the Ill Child. www.dh.gov.uk/en/Publicationsandstatistics/Publications/Publicationspolicyandguidance/Browsable/DH_4867832
Committee on Paediatric Emergency Medicine. Emergency preparedness for children with special health care needs. *Paediatrics* 1999; 104: 53.
The Scottish Government. (2006) Emergency Care Framework for Children and Young People in Scotland. www.scotland.gov.uk/Publications/2006/09/19153348/13
Dyer C. London hospital to face High Court for allegedly refusing to resuscitate disabled girl. *BMJ* 2004; 328: 125.
Dyer C. Hospital breached boy's human rights by treating him against his mother's wishes. *BMJ* 2004; 328: 661.

Leaflet produced by Toni Mathieson and Kay Green, parents of disabled children in Sunderland, together with Dr Karen Horridge Consultant Paediatrician (Neurodisability) Sunderland UK (email: karen.horridge@nhs.net)

February 2011 Project funded by the Department of Health in England