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'User views of Emergency Health Care Plans for disabled children and young people'

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SIR—When a disabled child or young person becomes acutely unwell, prompt and appropriate action is essential. Emergency and front-line staff may not be familiar with the child's specific case or underlying condition, but require accurate background information to inform assessment. Disabled children are less likely to be able to indicate what is wrong and may not show the usual signs of illness. However, for the family, giving an explanation of the condition, associated difficulties, and often lengthy medication list, can be very frustrating in the acute situation and may be perceived to delay assessment of the immediate concerns.

Emergency Health Care Plans (EHCP) are produced for disabled children and young people in Sunderland, UK, towards improving communication when acute health care is required. Such plans are widely recommended in the United Kingdom and United States for children with chronic conditions.^{1–3} Wolff and colleagues looked at the process of developing and content of personal resuscitation plans for children with life-limiting conditions concluding these to be acceptable for families.⁴ There have been cases, leading to High Court action, where Accident and Emergency department staff have disregarded the verbal wishes of parents to initiate or not to initiate resuscitation for disabled children presenting with an acute deterioration in their condition.^{5,6} However, to our knowledge there is little information in the literature about the experience of using broader based EHCP such as those being developed in Sunderland.

Each EHCP contains basic demographic, diagnostic, and management information, including a statement about agreed levels of care (symptom control always, including specific advice for the individual; resuscitation

or not, intensive care or not, etc.), is typed onto two sides of A4 paper, laminated, and follows the child in all settings to be shown if a health emergency arises. They have been approved by City Hospitals Sunderland NHS Foundation Trust's Clinical Governance Committee as complying with the Trust's 'Do Not Attempt Resuscitation' Policy.

An audit ascertained the views of parents, carers, and professionals regarding the usefulness of these plans using semi-structured interviews. For 22/28 children identified by 1 January 2007 as having an EHCP, parents, carers, and professionals were interviewed (the Community Children's Nurses advised against contacting two families who were having particular difficulties coping with their child's diagnosis and clinical condition at the time, and four families were not contactable during the study period). All parents said that they understood why the plan had been written.

Parents reported the plan useful in all 12 cases where it had been used in an emergency. Although four parents found discussions about appropriate levels of care difficult, all understood the need for this and valued the inclusion of a statement about agreed levels of care in the plan. Seven plans stated 'allow natural death' or an equivalent phrase. In each of these cases, the resuscitation part of the plan had evolved over time reflecting progression in the child's condition and of discussions with the family.

Twenty-one out of twenty-two parents said that they found the plan easy to understand. One parent had found the section on medication confusing. Specific comments from parents included: '(It means that) junior doctors know about resuscitation, complex problems and treatment'; 'All emergency epilepsy information is there and they can get to his medication quickly'; 'No time wasted while she was very sick'. Twenty-four out of twenty-six staff had used an EHCP when managing an acutely unwell disabled child: all had found this helpful in assessing and managing the child and also when communicating with the family

and 22/24 found it facilitated communication between professionals about the child. Eighty-two per cent of parents and 100 per cent of staff reported finding the EHCP helpful overall in the acute setting. EHCP are

a simple tool that can facilitate communication and management for disabled children and young people; consideration should be given to preparing these in appropriate cases.

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'The International Cooperative Ataxia Rating Scale shows strong age-dependency in children'

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SIR—Many metabolic and neurodegenerative disorders in children are associated with relentlessly progressive ataxia. In order to attenuate disease progression, treatment strategies can involve the prescription of orphan drugs. When such innovative treatment strategies are applied in small, non-placebo-controlled pediatric patient groups, standardized, longitudinal, patient-based evaluations are frequently involved. Both in children and adults, the International Cooperative Ataxia Rating Scale (ICARS) is a commonly used evaluation, initially designed for longitudinal assessment of pharmacological therapies in patients with cerebellar ataxia.^{1–3} The ICARS is composed of four clinical sub-scores involving the following specific aspects: posture and gait, limb coordination, speech, and oculomotor function.⁴ The total sum of these sub-scores, the ICARS score, ranges from the optimal outcome '0' to the most severely affected outcome '100'. In children, the ICARS score has been applied for the evaluation of medication, such as in patients with Friedreich's ataxia or vitamin E deficiency^{5–8} and for the investigation of the relationship between cerebellar structure and function.^{9–11}

Until now, however, most of these trials compare their ICARS scores in children with adults instead of paediatric reference values.^{5–8,10} In young children, this may induce the risk that age-dependent achievement of fine motor skills, coordination, concentration, and muscle force influences the interpretation of ICARS outcome without interference of disease state, course, or therapy. Interestingly,

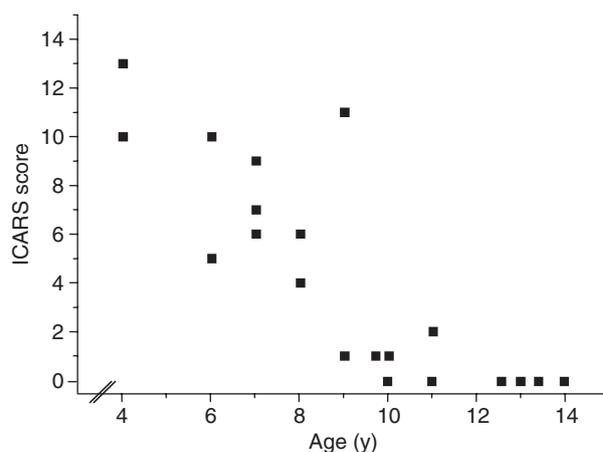


Figure 1: Cross-sectional International Cooperative Ataxia Rating Scale (ICARS) scores versus age in 20 healthy control children. ICARS scores decreased with age until the optimum ('0') was reached at about 13 years of age. $r = -0.85$ (polynomial regression).