

Stroke in Childhood

**Clinical guideline for diagnosis, management
and rehabilitation**

May 2017

Appendix 7

Contains:

- Parent engagement workshop

Royal College of Paediatrics and Child Health
5-11 Theobalds Road, London, WC1X 8SH

The Royal College of Paediatrics and Child Health (RCPCH) is a registered charity in England and Wales (1057744) and in Scotland (SC038299).

Appendix 7: Parent engagement workshop

Parent engagement workshop

Reason for the workshop

The stroke in childhood guidelines are currently under review, coordinated by the Royal College of Paediatrics and Child Health (RCPCH) with the support of the Stroke Association.

Little evidence exists to guide practice around information, support and transition needs of young people, parents and carers. To inform the content of the guideline around these aspects of care the experiences and opinions of young people and their parents or carers were sought.

Structure of the workshop

Parent and young person engagement workshops were held with the main objective being to elicit parent and young person feedback around specific components of care to ensure that the developed recommendations reflect the needs of the patients and their families.

The two workshops had the same format, discussed the same topics and were designed and facilitated by a clinical member of the guideline development group (GDG). The first workshop was specifically for parents who had a child who had an arterial ischaemic stroke (AIS), the second workshop was for parents and carers and children who had haemorrhagic stroke (HS).

At the first workshop there were nine parents in attendance, while during the second there were 12 attendants (three children/young people who had had a stroke and nine parents).

Methodology

Young people and their parents or carers were identified by members of the GDG, i.e. clinicians working with this population. Those consenting to be contacted by their clinicians were approached by the Stroke Association in collaboration with the RCPCH and invited to attend one of two workshop dates in central London (28 June and 22 July 2016). Invitees were offered travel cost reimbursement.

Consent was obtained in writing (and retained by the RCPCH) to have discussions recorded by note-takers present during the sessions. The workshops followed a set structure. Attendees were introduced to the guideline scope and process. The topics of focus for the workshop were described and the related scientific literature in this area summarised. The attendees were then divided into three groups. Each group had a facilitator and note-taker who covered one of the above three topics and rotated at set intervals, enabling all attendees to contribute to all topics.

Questions centred on:

- What information is most important for stroke patients and their families from diagnosis onwards?
- What do families need in terms of support and healthcare; and how could charities support access to care and rehabilitation for children after stroke?
- What are the most important things to have in place when moving from hospital to home; when moving through schooling; and when moving into adult education/healthcare?

Facilitators encouraged participants to draw upon their experiences, whether positive or negative, and make suggestions about what they considered the most important elements to consider and 'get right' in delivering support and care.

Following the workshop, transcriptions (including direct quotations) were reviewed. Data was coded by a research assistant who was not present during the workshops, then reviewed and refined by a second coder who was the workshop facilitator.

Initial review of the transcripts suggested overlap in responses across the three key questions. Data was therefore combined from across the two workshops and across the three key questions and analysed as a whole. The transcriptions were extracted in the form of key phrases. These phrases were then categorised into sub themes with notes to describe meaning through comparing with the remaining data. Finally a series of six overarching categories were generated and main findings abstracted from each category.

The six categories were:

- Communication – child and family centred, proactive, sensitive, and with time to ask questions
- Information – timing, modality and individualised content
- Support – personalised, consistent, regular contact
- Transition – planned, agreed, active involvement of families, focussed on independent living skills
- Care coordination – having a key worker or key contact to provide consistent support and help navigate systems
- Knowledge of professionals – knowledge of child stroke and/or the ability to access expert care and advice

