EACH Library Care Bulletin

From the EACH Library & Information Service

www.each.org.uk/library

Microsoft Online images

September 2026

The latest resources from a range of organisations, journals and web sites. If you have any ideas or feedback on what would be useful for future bulletins, please get in touch:
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1. Podcasts: Research to Reality in Rare Syndromes

The Cerebra Network is a UK research collaboration focused on understanding rare genetic syndromes associated with intellectual disabilities and autism. In July 2026, it launched a podcast series bringing together researchers, professionals and parent carers to discuss challenges, evidence and practical ways to support families. Their first 2 podcasts focused on sleep

When Sleep doesn't come easy –

In this episode, researchers discuss sleep in children with rare genetic syndromes, sharing evidence-based insights and practical advice to help families better understand and support their child's sleep. [*28 mins]*

Episode 1: When Sleep Doesn't ... - Research to Reality in Rare Syndromes - Apple Podcasts

Sleep Challenges in Children with Rare Syndromes: A Family Perspective

In this episode, a parent carer shares their experience of supporting a child with a rare genetic syndrome and severe sleep difficulties. The discussion explores the impact of sleep challenges on family life and highlights practical strategies that can help families manage them. *[41 mins]*.

Episode 2: Sleep Challenges in... - Research to Reality in Rare Syndromes - Apple Podcasts

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2. Article: How to prepare for participation in a simulation activity

This journal article explores the role of simulation-based learning in nurse education and highlights how anxiety can affect students' learning experiences. It outlines the importance of preparation, psychological safety, effective pre-briefing and structured debriefing in helping students engage confidently with simulation activities and maximise learning outcomes.

McGinty K, Leach N (2026) How to prepare for participating in a simulation activity. Nursing Standard. doi: 10.7748/ns.2026.e12755

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3. High-intensity treatment is common at the end of life among children and young people who died of cancer: a retrospective cohort study

This article examines end-of-life care for children and young people with cancer in England. It found that over half received high-intensity treatments in the final weeks of life, and nearly half died in hospital. The study highlights that while intensive treatment at the end of life is common, its appropriateness can be difficult to assess, and hospital remains the most common place of death.

Jarvis S, Damun P, Hinde S, *et al.* High-intensity treatment is common at the end of life among children and young people who died of cancer: a retrospective cohort study. *BMJ Paediatrics Open*, 2026;10:e004575. doi:10.1136/bmjpo-2026-004575

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4. Article: Patient deterioration: How Martha's Rule has been introduced in hospitals

This article reviews the impact of **Martha's Rule**, a patient safety initiative that enables staff, patients and families to escalate concerns about a deteriorating patient. Drawing on experiences from several NHS trusts, it shows how nurses are using the scheme to seek rapid reviews, raise concerns with greater confidence and support earlier intervention when a patient's condition may be worsening.

Trivedi, S.S. (2026) 'Patient deterioration: is Martha's rule helping to prevent tragedies?', *Learning Disability Practice*, 29(4), pp. 7-8

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5. An exploratory study of the feasibility and acceptability of a digital storytelling intervention in paediatric palliative care in Ireland

This study explored the use of digital storytelling with children receiving palliative care and their families in Ireland. With support from trained facilitators, five families created personalised videos using stories, photos, music and family memories.

Families found the experience meaningful and enjoyable, suggesting that digital storytelling offers a modern alternative to traditional memory-making by creating lasting digital keepsakes that capture children's voices and experiences.

Safarifard, R., et al. (2026) 'An exploratory study of the feasibility and acceptability of a digital storytelling intervention in paediatric palliative care in Ireland', *Journal of Pediatric Nursing*, 89, pp. 241-249.

Request a copy from the library

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6. Guide – Communicating with children with severe or profound intellectual disabilities

Updated in 2025, the guide from Cerebra helps family carers of children with severe to profound intellectual disabilities understand communication challenges and learn practical strategies to support effective communication. It also provides information on assessment, key concepts and useful resources. A useful guide for staff teaching on communication and behaviours that challenge.

Download here

7. Web site: FIND (Further Inform Neurogenetic Disorders)

Some of you may already be familiar with FIND but it was new discovery to the library a few weeks ago. FIND provides information, research updates and practical resources for families, carers and professionals supporting people with rare genetic syndromes, including Angelman syndrome, Cri du Chat syndrome, Cornelia de Lange syndrome, Fragile X syndrome and Prader-Willi syndrome, as well as several others. The website is well worth exploring, particularly the syndrome section and topic-based resources.

https://findresources.co.uk/

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8. Podcasts from 'The Calm in the Complicated'

Calm in the Complicated *is a series of podcasts for families who have ever felt overwhelmed, unseen, or alone while raising a child with a brain condition - The Calm in the Complicated Podcast*

Episode 3: Life Admin: Managing Paperwork When Your Child Has Complex Needs

Joined by Rachel Wright, founder of *Born at the Right Time*, parent of a young person with complex disabilities, the episode shares practical tips for managing the paperwork and admin that can feel like a second job. A reassuring listen for parents feeling overwhelmed by the systems around their child. *50 minutes.*

Episode 6: Looking After You: Mental Health & Wellbeing for Parents & Carers of Children with Brain Conditions

Caring for a child with a brain condition can be rewarding, meaningful and deeply joyful but it can also be exhausting, isolating and emotionally demanding. In this episode, Carrie and Sam explore the realities of burnout, mental health and wellbeing for parent carers, and why looking after yourself is not a luxury but a necessity. *45 minutes.*