EACH Library Care Bulletin

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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. Podcast: Dad's Still Standing – Spotlight on loss with Rev. Kate Bottley

Building on their earlier episode about religion and baby loss, this conversation offers a new lens of what it's like to stand beside grieving parents as the person conducting their child's funeral. The episode is a reminder that grief doesn't follow a script – and neither does belief.

Available here – 50 mins.

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4. Article: Using the national Paediatric Early Warning Score System (PEWS) in England : Part 1

For those who teach on the use of PEWS, a good detailed article on the assessment, documentation and scoring of a child's vital signs and observations to calculate a PEWs score. It also outlines the assessment and documentation of other important physiological parameters that don't contribute to the PEWS score but inform the escalation level and actions to take.

England AM, Temporin A, Hornsby V et al (2025) Using the national Paediatric Early Warning System (PEWS) for England: part 1. Nursing Children and Young People. doi: 10.7748/ncyp.2025.e1543

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Article: Assessing the use of the distress and discomfort assessment tool (DisDAT) in a pediatric population

US research on the use of the DisDAT tool in non verbal children and the experience of caregivers who used the tool. Building on the research already carried out in adults with communication challenges, the DisDat was found to be an effective tool to communicate distress signals for non speaking children.

Parks, R., Meyer, J., Sund, G., Lam, T., Ramji, L. and Karlin, D., 2025. Assessing the use of the distress and discomfort assessment tool (DisDAT) in a pediatric population. *Journal of Pediatric Nursing*, *83*, pp.140-145.

Download here. More information and the tool from St Oswald's Hospice

4. Article: Parents' experiences of the financial and employment impacts of their child receiving end-of-life care: a national qualitative study

In this UK research, 42 interviews took place with 55 parents, recruited from NHS sites, children's hospices and via social media of other charities. A really insightful article about the financial stress and employment difficulties for families when their child is receiving end of life care and after their death. A number of recommendations are made.

> *'Families who were in receipt of disability living allowance quickly found they were no longer eligible for this financial support once their child had died. The swiftness of the system to recognise the change in circumstances and stop payments was an added shock especially given the lengthy delays they faced when making their application for support.'*

Barrett, L., Peat, G., McLorie, E.V., et al. 2025. Parents' experiences of the financial and employment impacts of their child receiving end-of-life care: a national qualitative study. *BMC Palliative Care*, *24*(1), pp.1-10.

Download here

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6. Report: Family Fund: The cost of caring 2025

The Family Fund Cost of Caring 2025 report published last week draws on responses from more than 2,300 families raising disabled or seriously ill children across the UK.

'Our new research shows that UK families raising disabled or seriously ill children and young people are being driven further into debt and unable to meet vital extra caring costs.'

Read key findings and full report here

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10. Article: Strategies for supporting neurodivergent nursing students in practice placements

Neurodivergent conditions include autism, attention deficit hyperactivity disorder (ADHD) and dyslexia and an increasing number of people with these conditions are entering higher education. Despite the best intentions of staff, these students' placement experiences and outcomes can be adversely affected, and without appropriate support they may become less likely to engage with some learning opportunities. This article provides an overview of some of the challenges that neurodivergent nursing students may experience during their placements, and outlines some potential strategies that staff supporting them can use.

Ripley KR (2025) Strategies for supporting neurodivergent nursing students in practice placements. Nursing Standard. doi: 10.7748/ns.2025.e12460

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5. EAPC Blog: Being listened to and believed matters for equality in palliative care

European Association for Palliative Care

One voice, one vision for palliative care

An interesting read about the unconscious bias of healthcare professionals supporting and working with families from social disadvantage or hardship. It introduces a new framework – the Cognitive Authority Theory framework to facilitate open and non-judgemental listening and knowledge sharing.

> *"Imagine a parent who has experienced a life of social deprivation and hardship, sitting in a multidisciplinary team meeting about the care of their dying child. They know their child better than anyone and speak from lived experience with insight and urgency. Yet they feel small, surrounded by professionals with qualifications, institutional authority and recognised expertise …..Their voice is less credible, not because it lacks truth, but because it lacks status."*

Being listened to and believed matters for equality in palliative care | EAPC Blog

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8. Article: How to prime and connect an intravenous administration set

From the Nursing Standard *'How To'* series, a very good article for those who train on IV practice or for staff wanting to update themselves in practice. Useful to check against any hospice OR NHS Trust Standard Operating Procedures (SOPs).

Munro C (2025) How to prime and connect an intravenous administration set. Nursing Standard. doi: 10.7748/ns.2025.e12509

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7. Article: "*Holding Families in Uncertainty*": A Framework Analysis of the Role and Impact of Children's Hospices in the Provision of Perinatal Palliative Care

The aim of this hospice based research was to better understand how children's hospices contribute to the care of babies and their families where a need for palliative care has been recognised. 18 healthcare practitioners took part from 3 children's hospice services. A lack of awareness of the role of hospices was described as the biggest barrier to referral to hospice services. Practitioners unanimously described having a physical presence alongside hospital based teams on NICU, as being the biggest contributor to improved multiagency working.

> *"we've found that it's not always necessary to have a set purpose or reason to be on the [neonatal] unit, or to sit with families during consultations and appointments. There's no agenda, but it's about us holding families in their uncertainty, letting them know that there are options, and that its okay to talk about any or all of them, at any time."*

Tatterton, M.J., Fisher, M.J., Storton, H., McShane, Z.P. and Walker, C., 2025. "Holding Families in Uncertainty": A Framework Analysis of the Role and Impact of Children's Hospices in the Provision of Perinatal Palliative Care. Illness, Crisis & Loss, 33(1), pp.152-171.

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9. Toolkit: Starlight and the NHS The Play Well Toolkit

For those staff particularly interested in play and ensuring it's built into every aspect of children's care, here's a new toolkit, comprising of Guidance, 7 Key organisational Standards and a Quality Checklist to use as a benchmark, ensuring play is embedded into children's services, staff training and part of a child's care.

Starlight | NHS Play Well Toolkit

9 Parent Information Leaflets from SNAP

Over the last few months, the Essex based charity SNAP has added some really informative resources for families with children with additional needs or disability. Here's a selection of them with many more of their web site. Ideal for staff new to working with children with complex needs to get a general overview of a topic.

Postural-Care-Night-Time-Positioning.pdf

Talking-About-a-Diagnosis.pdf

Eating.pdf

Emotional-regulation-and-zones.pdf

Puberty.pdf

Sleep.pdf