EACH Library Care Bulletin

From the EACH Library & Information Service

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The latest articles, guidance and resources from a range of 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: Respecting your sensory self with Joanna Grace

The Skies We're Under podcast is created by and for parents of children with disabilities and the many practitioners who support them. In this podcast, their guest is Joanna Grace, sensory engagement and inclusion specialist. She talks about the fundamentals of sensory development, and shares a wealth of tips for providing a rich sensory landscape for a child as well as a parent/carer.

Listen<u>here</u> – 53 minutes

2. Website: Wilbo's Blends - blended feeds for enteral feeding

A useful resources/web site for staff supporting or talking to families about changing to a blended diet for their child. It includes lots of practical information from equipment, health improvements, getting started and health and safety issues.

All resources - blended diet - tube feeding - Wilbo's Blends — Wilbo's Blends

3. Article: Silly sessions and the benefit of laughter

From the PMLD Link Journal, an interesting read on how to create a 'silly session' that supports developing interoceptive awareness and self-regulation through silly playful interactions with children, who are neurodiverse. It describes using it in classroom and also 1:1 settings.



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Claire Campbell, Silly sessions and the benefits of laughter. PMLD. Winter 2024. Vol 36 (3). Pages 8-9.

Contact the library for a copy

4. A short guide: Making memories....

Published last year by the Irish Palliative Care Network, and written by mums from the "Mothers of Extra Special Kids Ireland Facebook page', it details how they approached making their own memories, It notes:

'When your child is very sick it can be hard to imagine making memories...... On top of everything else, you are told to make special times. Usually memories are just there....'



Download here: <u>Making_memories_D.pdf</u>

5. A short guide: Things we wish we knew...



Also written by mums from the "Mothers of Extra Special Kids Ireland Facebook page', the guide has 2 topics: Dealing with medical professionals and Looking after yourself. It notes:

'Treat this booklet like a tool kit. Some tools you may need right now. Many you might never need. The rest of the tools are here if you need them.'

Download here: <u>ThingsWeWishKnew_finished.pdf</u>

6. Article: Medicines management in children and young people: pharmacological approaches to treat pain.

Pain management in children is often more complex than in adults, since pain in children can be more challenging to assess and therefore more challenging to treat. The article provides an overview of the three main groups of analgesics – non-opioids, opioids and adjuvants – that can be used in the pharmacological management of pain in children and young people.

Davies K (2024) Medicines management in children and young people: pharmacological approaches to treat pain. Nursing Children and Young People. doi: 10.7748/ncyp.2024.e1540

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7. Article: Recognising uncertainty: an integrated framework for palliative care in perinatal medicine

Developed collaboratively by the British Association of Perinatal Medicine (BAPM) and the Association of Paediatric Palliative Medicine (APPM), the framework provides guidance on recognising babies who may benefit from palliative care and outlines the key elements of perinatal palliative care: holistic family support, empowering parents to be parents, parallel planning, symptom management and loss and bereavement care

Wilkinson D, Bertaud S, Mancini A, et al. Arch Dis Child Fetal Neonatal Ed Epub ahead of print doi:10.1136/archdischild-2024-327662

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8. Article: How to auscultate for heart sounds in children in infants and children



This article provides a good introduction to performing cardiac auscultation in infants and children aged 0-16 years, with the aim of improving children's nurses' knowledge and confidence in this procedure. It provides a thorough explanation of all aspects, along with background information but does note that it's not intended to demonstrate an individual's competence.

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Westley E, Renwick C, Ellis E (2024) How to auscultate for heart sounds in infants and children. Nursing Children and Young People. doi: 10.7748/ncyp.2024.e1527

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9a. Podcast: Raising a child with disabilities

From the Podcast series *Therapy Works*, Julia Samuels talks to Heather the mum of Lizzie who has profound and multiple learning disabilities. Themes discussed include living with profound disabilities, parental chronic sorrow, finding meaning and coping and connecting with others with the same experiences.

47 minutes listen

9b. And also an article written by Heather – My Beautiful Girl....

If you don't have time for the Podcast above, you can read an article written by Heather in this month's PMLD magazine, covering the same themes. It features a letter Heather wrote to her daughter Lizzie when her daughter turned 16, twelve years ago and was part of Julia Samuel's Therapy Work 'Unheard voices' Project. It's a particularly good read for those perhaps new to working in children's hospices and getting an insight into parenting a child with very profound disabilities. She wrote:

"I no longer compare you to others although milestones can still be painful"

Heather Bailey. My Beautiful Girl. PMLD. Winter 2024. Vol 36 (3). Pages 14-16.

Contact the library for a copy

Upcoming Webinars – Friday 17th January 12.30 – 2pm.

Crisis Prevention not Crisis Management: the health and wellbeing of parents and children with life-limiting conditions. Presented by Professor Lorna Fraser, Victoria Fisher and Sue Hogg

With the growing numbers of children with life-limiting conditions, it is often expected that parents of these children become healthcare providers as well as parents, 24 hours a day, 7 days a week. The webinar presents findings from studies of the health and wellbeing of parents before also highlighting the mental health needs of the children themselves.