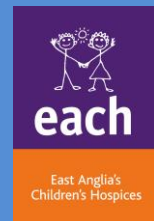


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Quarterly bulletin focusing on children with complex needs and neurodisabilities

August 2023 ~ library@each.org.uk



Bulletin No. 1 (Jan – August 2023)

Please note this first bulletin is an extended version

1. Psychosocial Measures and Outcomes Among Caregivers of Children With Tracheostomies: A Systematic Review

Authors: Acorda, Darlene E.; Brown, Jennifer N.; Lambert, Elton M. and Gibbs, Karen DiValerio

Journal: Otolaryngology - Head & Neck Surgery 2023 168(5), pp. 979-987

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36939578/>

2. Exploring the Use of Arts-Based Interventions and Research Methods in Families of Seriously Ill Children: A Scoping Review.

Authors: Bally, Jill M. G.; Burles, Meridith; Spurr, Shelley et al.

Journal: Journal of Family Nursing 2023 10748407231165119

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37128884/>

3. Changes in UK paediatric long-term ventilation practice over 10 years.

Authors: Barker, N., et al

Journal: Archives of Disease in Childhood 2023 108(3), pp. 218-224

PubMed Link: <https://pubmed.ncbi.nlm.nih.gov/36446480/>

4. What makes a home? Designing home personas to represent the homes of families caring for children with medical complexity.

Authors: Barton, H. J., et al

Journal: Applied Ergonomics 2023 106

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36122551/>

5. Current and emerging pharmacotherapy for the treatment of Lennox-Gastaut syndrome.

Authors: Besag, F. M. C.;Vasey, M. J. and Chin, R. F. M.

Journal: Expert Opinion on Pharmacotherapy 2023

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37212330/>

6. Fenfluramine treatment for Dravet syndrome: Caregiver- and clinician-reported benefits on the quality of life of patients, caregivers, and families living in Germany, Spain, Italy, and the United Kingdom.

Authors: Jensen MP, Gammaitoni AR, Salem R,et al.

Journal: Epilepsy Res. 2023 Feb;190:107091.

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36701932/>

7. Implementing Spiritual Care in the Pediatric Complex Care Clinic.

Authors: Brand, E. A. J.;Shaw, M. and Galo, J.

Journal: The Journal of Pastoral Care & Counseling : JPCC 2023 77(1), pp. 27-33

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36062721/>

8. Is baclofen the least worst option for spasticity management in children?

Authors: Brandenburg, J. E.

Journal: Journal of Pediatric Rehabilitation Medicine 2023 16(1), pp. 11-17

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36938744/>

9. Parental Perception and Barriers Regarding COVID-19 Vaccination in Technology Dependent Children.

Authors: Capusan, K. Y.;Rebaza, A. P.;Santiago, M. T. and Quizon, A.

Journal: Journal of Pediatric Health Care 2023

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37227325/>

10. School Attendance Decisions for Children With Medical Complexity During COVID-19.

Authors: Collier, R. J., et al

Journal: Pediatrics 2023 152 (Supplement 1)

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37394510/>

11. Design and Administration of Patient-Centred Outcome Measures: The Perspectives of Children and Young People with Life-Limiting or Life-Threatening Conditions and Their Family Members

Authors: Coombes, Lucy, et al

Journal: The Patient 2023 , pp. 1-11

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37221441/>

12. Gut dysmotility in children with neurological impairment: the nutritional management.

Authors: Corsello, A., et al

Journal: Frontiers in Neurology 2023 14

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37213895/>

13. Clinician and carer moral concerns when caring for children who tube-feed.

Authors: Dadich, A., et al

Journal: Journal of Child Health Care 2023 27(2), pp. 182-196

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/34696607/>

14. Hospital-to-home transitions for children with medical complexity: part 1, a systematic review of reported outcomes.

Authors: de Lange, A., et al

Journal: European Journal of Pediatrics 2023

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37318656/>

15. Effect of the ketogenic diet as a treatment for refractory epilepsy in children and adolescents: a systematic review of reviews.

Authors: DiezArroyo, C., et al

Journal: Nutrition Reviews June 2023

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37400987/>

16. The collective burden of childhood dementia: a scoping review

Authors: Elvidge, Kristina L., et al

Journal: Brain : A Journal of Neurology 2023

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37471493/>

17. Childhood Dementia: A Collective Clinical Approach to Advance Therapeutic Development and Care.

Authors: Djafar, J. V.; Johnson, A. M.; Elvidge, K. L. and Farrar, M. A.

Journal: Pediatric Neurology 2023 139, pp. 76-85

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36571866/>

18. Making Polypharmacy Safer for Children with Medical Complexity.

Authors: Feinstein, J. A. and Orth, L. E.

Journal: Journal of Pediatrics 2023 254, pp. 4-10

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36252865/>

19. Feeling stretched: Parents' narratives about challenges to resilience when their child has a tracheostomy

Authors: Flynn, Alison; Whittaker, Karen; Donne, Adam J.; Bray, Lucy and Carter, Bernie

Journal: Journal of Child Health Care

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37050871/>

20. Central venous access in children: Placement trends over the last decade.

Authors: Gaballah, Marian, et al

Journal: Clinical Imaging 2023 97, pp. 84-88

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36921450/>

21. New treatments in spinal muscular atrophy

Authors: Gowda, Vasantha Lakshmi; Fernandez-Garcia, Miguel A. et al.

Journal: Archives of Disease in Childhood 2023 108(7), pp. 511-517

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36316089/>

22. Deprivation of liberty and children with complex needs: a new specialist court

Authors: Griffith, Richard

Journal: British Journal of Nursing (Mark Allen Publishing) 2023 32(9), pp. 450-451

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37173084/>

23. Dilemmas in feeding infants with intestinal failure: a neonatologist's perspective.

Authors: Hair, A. B. and Good, M.

Journal: Journal of Perinatology 2023 43(1), pp. 114-119

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36127395/>

24. Experiences of Health Care and Psychosocial Needs in Parents of Children with Spinal Muscular Atrophy

Authors: Inhestern, Laura, et al

Journal: International Journal of Environmental Research and Public Health 2023 20(7), pp. 5360.

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37047974/>

25. Care management trajectories of infants with life-limiting conditions who died before 12 months of age; a retrospective patient health record review

Authors: Iten, Rebecca; O'Connor, Moira; Cuddeford, Lisa and Gill, Fenella J.

Journal: Journal of Pediatric Nursing 2023 70, pp. e22-e31

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36463014/>

26. Shared decision-making for children with medical complexity in community health services: a scoping review

Authors: Jacobs, Sonja, et al

Journal: BMJ Paediatrics Open 2023 7(1), pp. 04

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37012004/>

27. Employment and leave while parenting children with medical complexity.

Authors: Kellom, K. S.;WilsonHall, C. L.;Strane, D.;Wu, K. and Matone, M.

Journal: Families, Systems & Health : The Journal of Collaborative Family Healthcare 2023 41(2), pp. 168-181

PubMed link

28. The Use of Blended Diets in Children with Enteral Feeding Tubes: A Joint Position Paper of the ESPGHAN Committees of Allied Health Professionals and Nutrition.

Authors: Koglmeier, J., et al

Journal: Journal of Pediatric Gastroenterology and Nutrition 2023 76(1), pp. 109-117

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36053165/>

29. "Between Wings of Hope and Fear": Muslim Parents' Experiences with the American Health Care System

Authors: Kolmar, Amanda;Kamal, Arif H. and Steinhauser, Karen E.

Journal: Journal of Palliative Medicine 2023 26(1), pp. 73-78

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/35861545/>

30. Long-term non-invasive ventilation in children: Transition from hospital to home.

Authors: MacLean, J. E. and Fauroux, B.

Journal: Paediatric Respiratory Reviews Jan 2023

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36806331/>

31. Crossing the line? Ethics of parenteral nutrition in paediatric neurodisability complicated by intestinal failure

Authors: McCallum, Zoe;Delany, Clare and Gillam, Lynn

Journal: Archives of Disease in Childhood 2023 108(1), pp. 11-14

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/35288420/>

32. Blended diet for enteral tube feeding in young people - a systematic review of the benefits and complications.

Authors: McCormack, S.;Patel, K. and Smith, C.

Journal: Journal of Human Nutrition and Dietetics : The Official Journal of the British Dietetic Association
24 Jan 2023

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36692240/>

33. International project on troublesome symptoms in paediatric palliative care will focus on neuro-irritability, dystonia and sleep disorders.

Authors: Avagnina I, Giacomelli L, Mercante A, Benini F et al:

Journal: Acta Paediatr. 2023 Mar;112 (3): 569-570.

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36627263/>

34. Parent-to-parent support for childhood neurodisability: A qualitative analysis and proposed model of peer support and family resilience

Authors: McCrossin, Jeffrey and Lach, Lucyna

Journal: Child: Care, Health and Development 2023 49(3), pp. 544-554

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36222028/>

35. Provision of care for children with medical complexity in tertiary hospitals in England: qualitative interviews with health professionals

Authors: McLorie, Emma Victoria; Fraser, Lorna and Hackett, Julia

Journal: BMJ Paediatrics Open 2023 7(1), pp. e001932. doi: 10.1136/bmjpo-001932

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37451703/>

36. Cannabidiol for the treatment of refractory epilepsy in children: a critical review of the literature.

Authors: Moreira, G. A. ;Neto, R. M.; Ribeiro, R. G. and De Souza Crippa, A. C.

Journal: Revista Paulista De Pediatria 2023 41

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/35830160/>

37. Hospital Access Patterns of Children With Technology Dependence.

Authors: Moynihan, K.; Franca, U. L.; Casavant, D. W.; Graham, R. J. and McManus, M. L.

Journal: Pediatrics 2023 151 (4)

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36938610/>

38. Investigational new drugs for the treatment of Dravet syndrome: an update

Authors: Janković SM, Janković SV, Vojinović R, et al.

Journal: Expert Opinion Investig Drugs. 2023 Apr; 32 (4): 325-331.

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36932738/>

39. Transforming nursing care for children with serious long-term conditions: A mixed methods exploration of the impact of Roald Dahl Specialist Nurses in the United Kingdom.

Authors: Nightingale, Julie, et al

Journal: Journal of Pediatric Nursing 2023 70, pp. 90-102

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36848741/>

40. Navigating the path home: pioneering hospital-to-home transitions for children with medical complexity.

Authors: Peters, V. J. T. and de Winter, J. P.

Journal: European Journal of Pediatrics June 2023

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37368005/>

41. Integrated care for children living with complex care needs: navigating the long and winding road.

Authors: Peters, Vincent J. T. and de Winter, J. Peter

Journal: European Journal of Pediatrics 2023 182(4), pp. 1437-1438

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36862224/>

42. Exploring the experience of family caregivers of children with medical complexity during COVID-19: a qualitative study.

Authors: Pitch, Natalie, et al

Journal: BMC Pediatrics 2023 23(1), pp. 160

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37024854/>

43. What are the priority needs for those caring for children and young people with complex neurodisability within an ethnically diverse UK context? - The feasibility phase of the ENCOMPASS study.

Authors: Prest, K., et al

Journal: medRxiv 2023: 27 Mar 2023

Read more here: <https://www.medrxiv.org/content/10.1101/2023.03.23.23287248v1>

44. Use of home parenteral nutrition in severely neurologically impaired children.

Authors: Ribeiro Mourao, F., et al

Journal: Archives of Disease in Childhood 2023

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/34551897/>

45. Medication Rounds: A Tool to Promote Medication Safety for Children with Medical Complexity.

Authors: Rojas, Christina R., et al

Journal: Joint Commission Journal on Quality & Patient Safety 2023 49(4), pp. 226-234

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36775713/>

46. Length of Stay and Barriers to Discharge for Technology-Dependent Children During the COVID-19 Pandemic.

Authors: Rush, Margaret, et al

Journal: Hospital Pediatrics 2023 13(1), pp. 80-87

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36519266/>

47. Antibiotics for chronic pulmonary infection in children with a neurodisability (neurodevelopmental disorder)

Authors: Sanner, Juliane R; Jain, Kamini; Williams, Jane et al.

Journal: The Cochrane Database of Systematic Reviews 2023 2(2),

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36757320/>

48. The burden of central line-associated bloodstream infections in children with medical complexity.

Authors: Scarselli, Alessia, et al

Journal: Journal of Vascular Access 2023 24(2), pp. 198-204

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/34148383/>

49. "What Would Give Her the Best Life?": Understanding Why Families Decline Pediatric Home Ventilation.

Authors: Shipman, K. J., et al

Journal: Journal of Palliative Medicine 2023 20 Jan 2023

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36662553/>

50. Is it too complex? A survey of pediatric residency program's educational approach for the care of children with medical complexity.

Authors: Sieplinga, K.; Kruger, C. and Goodwin, E.

Journal: BMC Medical Education 2023 23(1), pp. 331

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37170096/>

51. "What I Would Do to Take Away Your Pain": A Photovoice Project Conducted by Mothers of Children With Medical Complexity

Authors: Sonsteng-Person, Melanie, et al

Journal: Qualitative Health Research 2023 33(3), pp. 204-219

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36704955/>

52. Ethics Roundtable: How Much is Too Much?

Authors: Theodoro, Mariana F.; Hays, Jacinda; DiBartolomeo, Mara and Carter, Brian

Journal: The American Journal of Hospice & Palliative Care 2023 40(1), pp. 106-110

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/35466683/>

53. Navigating two 'truths': a qualitative study of physician-led end-of-life decision-making for children with life-limiting conditions.

Authors: Vemuri, S.;Hynson, J.;Williams, K. and Gillam, L.

Journal: Archives of Disease in Childhood 2023 Date of publication: 15 May 2023

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37188494/>

54. User-perceived impact of long-term mechanical assisted cough in paediatric neurodisability.

Authors: Hov B, Andersen T, Toussaint M, et al.

Journal: Dev Med Child Neurol. 2023 May; 65 (5) :655-663.

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36787316/>

55. Family-Reflections.com: Creating a parent-to-parent web-based tool regarding pediatric home ventilation.

Authors: Vo, H. H., et al

Journal: Patient Education and Counseling 2023 114(pagination), date of publication: September 2023

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/37348312/>

56. It takes a village to raise a child with a tracheostomy: Translating principles into practice.

Authors: Ward, E.;Pandian, V. and Brenner, M. J.

Journal: Journal of Clinical Nursing 2023 32(13-14), pp. 4199-4202

PubMed link: <https://pubmed.ncbi.nlm.nih.gov/36183198/>



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