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| **Title** | **Management of Long Term Conditions (LTC) in Children** |
| **Code** | **MDM159** |
| **Level** | 7 |
| **Credit rating** | 20 Credits |
| **Pre-requisites** | This module is aimed at paediatricians and other health care  professionals who are, or are planning to, work with children with long term  conditions and would like to enhance their knowledge. |
| **Type of module** | 5 days delivered over a week – Mo-Fri |
| **Aims** | This module aims to:  • Enhance understanding of the multi-disciplinary approaches to  managing long term conditions in children  • Develop knowledge and skills in the different aspects of long  term care like accountability, communication skills, record  keeping and promotion of dignity and health  • Analyse current thinking in long-term conditions management  and discuss the difficulties faced by the children and their  families living with long-term health conditions.  This module will enable you to understand multi-disciplinary approaches to managing long term conditions in children and to develop insight into evidence-based practice, in the clinical, social and psychological aspects of management involved in these conditions. The module is clinically focused and non-disease specific. You will develop a critical understanding of the research, policies and practice relating to long term conditions in various organisational contexts and you will have the opportunity to network with professionals from different disciplines and share best practice. |
| **Learning outcomes/objectives** | Upon successful completion of the module, students should be able to:  ILO1. Demonstrate a comprehensive knowledge of the pathophysiology of long term conditions which affect children.  ILO2. Systematically describe and critically evaluate the principles of  management of long term conditions in children.  ILO3. Enhance understanding of the role of multidisciplinary teams in managing children with long term conditions.  ILO4. Apply knowledge to develop a case study and appropriate  management plan for a child with a specific long term condition.  ILO5. Demonstrate an awareness of the psycho-social impact of long term conditions on children and their families.  ILO6. Prepare a poster presentation of a case study, |
| **Content** | **Principles of management of LTC in children**  • Pathophysiology of long term conditions  • Aetiology and disease progression of selected LTC (Asthma, Cystic Fibrosis, Inflamm Bowel Dis, Diabetes, Oncology, Epilepsy, Congenital Heart Disease, Metabolic diseases, Cerebral Palsy and Sickle Cell disease)  • First and ongoing clinical evaluation of a child with LTC  • Investigational approach with a child with LTC  • Medical treatment strategy for children with LTC  **Multidisciplinary approach**  • Role of Multidisciplinary teams in managing children with  long term conditions  • Benefits and support to children with LTC and their families  • The psychosocial impact of long term conditions on children  and their families and models of adherence.  **Service organisation**  • Transitional care arrangements for long term conditions  when children are ready to move to adult services  • Legal and ethical issues including consent  • Challenges and possible solutions for children with LTC  • Gaps in the service and future plans |
| **Teaching and learning strategies** | Teaching methods will encompass:   * Lectures * Group Discussion * Workshops * Student presentations * Individual project work * Self-directed learning * Reflection * Role play and simulations * Audio-visual and e-learning * “TED” talks   Learning will be supported further by the use of prepared notes, selected reading and all usual visual aids. Students will be expected to support their learning by the use and critical appraisal of primary sources of information such as peer-reviewed research articles and appropriate websites. Tutorial staff will outline key sources of information during their individual contact sessions.  Appropriate Course materials will be made available on ‘Studentcentral’: <http://studentcentral.brighton.ac.uk> |
| **Learning support** | **Literature Searching**  You will have been shown the basics of searching electronic databases (in particular Medline and Cinahl) during the Graduate Programme Induction. You will be expected to develop your searching skills to ensure all relevant literature for your assignment is accessed. You are expected to establish for yourselves a database of current theoretical and empirical articles and texts. These will be drawn upon to complete your assignments. Access to tutorials on this topic are available via the on-line library or at the libraries which you are strongly advised to set up.  **ASK Study Guide**  In addition to course-specific guidance, online resources to help you study effectively are available through the ASK Study Guide on Studentcentral. ASK offers advice on how to make the most of seminars and lectures, reading and note-making, preparing for exams, tackling stress, essay writing, oral presentations, group work and many other topics. You will also find information about the weekly Study Support workshops held at all university sites and specialist services such as the Maths & Stats Support Unit and English Language Support Programme.  **READING LIST**  **Books**  Brown E, Warr B. Supporting the Child and the Family in Paediatric Palliative Care. Jessica Kingsley Publishers; 2007.  Hanas, Ragnar. Type 1 Diabetes in Children, adolescents and young adults. 6th Edition. 2015.  Hewitt-Taylor J. Providing Support at Home for Children and Young People Who Have Complex Health Needs. John Wiley & Sons; 2008  Hewitt-Taylor J. Children with Complex and Continuing Health Needs: The Experiences of Children, Families and Care Staff. Jessica Kingsley Publishers; 2007  Kliegman R, Nelson WE. Nelson Textbook of Paediatrics. 19th ed. Philadelphia, PA: Elsevier/Saunders, 2011  Lissauer, T and Carroll, W, Editors. Chapter 17 Respiratory Medicine (section on Asthma). In: Illustrated Textbook of Paediatrics, Elsevier, 5th Edition.  Mukhopadhyay, Somnath. Chapter 6: The Unfinished Consultation. In: Treating Body and Soul. Editor Wells, P; Publisher Jessica Kingsley, London and Philadelphia. 2017.  Rodgers, J. Using Insulin Pumps in Diabetes: A guide for nurses and other health professionals. Wiley Publication. 2008.  Teare J. Caring for Children with Complex Needs in the Community. John Wiley & Sons; 2009  **Web links**  Association for Young People’s Health Briefing Paper: Long Term Conditions Research Summary. [Internet] published February 2012. Available from: http://www.ayph.org.uk/publications/242\_Final%20Summary%20RU9%20Long-term%20Conditions%20Feb%202012.pdf  Bromley London Borough. A new approach to special educational needs and disability 0 – 25. [Internet] published July 2014. Available from: https://bromley.mylifeportal.co.uk/media/14360/a-new-approach-to-sen-web-version.pdf  BTS/SIGN Asthma Guidelines 2016 [Internet] 2016. [accessed 2017 23 Oct]. Available at: https://www.brit-thoracic.org.uk/document-library/clinical-information/asthma/btssign-asthma-guideline-2016/  CCLG. AFTERcure: I had cancer as a child. Available at: https://www.cclg.org.uk/I-had-cancer-as-a-child  Coalition for Collaborative Care: Action for Long Term Conditions. Our Vision for the Future [Internet] published 21 Nov 2014. Available at: http://coalitionforcollaborativecare.org.uk/ Department for Education and Health. Special educational needs and disability code of practice:0 to 25 years. [Internet]. 2014. [accessed 2017 23 Oct]. Available from: https://www.gov.uk/government/publications/send-code-of-practice-0-to-25  Department for Education. Supporting pupils with medical conditions at school. [Internet]. 2014. [accessed 2017 23 Oct]. Available from: https://www.gov.uk/government/publications/supporting-pupils-at-school-with-medical-conditions--3  Joint Epilepsy Council. Epilepsy prevalence, incidence and other statistics. [Internet] September 2011 Available at: www.jointepilepsycouncil.org.uk  King’s Fund. Avoiding Hospital Admissions What does the research evidence say. [Internet] published 16 December 2010. Available from: https://www.kingsfund.org.uk/publications/avoiding-hospital-admissions  NHS England. National Action for local change Our declaration – person-centred care for long term conditions. [Internet] published 1 Sep 2015. Available at: https://www.england.nhs.uk/wp-content/uploads/2015/09/nat-act-chang.pdf  NICE National Institute for Health and Care Excellence. Epilepsies: diagnosis and management CG137. [Internet] Clinical guideline published 11 January 2012. Available from: Nice.org.uk/guidance/cg137  NICE Prophylaxis against infective endocarditis: antimicrobial prophylaxis against infective endocarditis in adults and children undergoing interventional procedures. [Internet] published March 2008. Available at: https://www.nice.org.uk/guidance/cg64  NICE Transition from children’s to adults’ services for young people using health or social care services. [Internet] published 24 Feb 2016. Available at: https://www.nice.org.uk/guidance/ng43  Sign guidelines SIGN 132 Long term follow up of survivors of childhood cancer [Online] Published March 2013 Available at: https://www.sign.ac.uk/assets/sign132.pdf  Latest Guidelines on professional organisations – British Society of Paediatric Endocrinology & Diabetes (www.bsped.org.uk), Association of Children’s Diabetes Clinicians (www.a-c-d-c.org), European Society of Paediatric Endocrinology (www.eurospe.org) and International Society of Paediatric and Adolescent Diabetes (www.ispad.org).  **Please also see following links:**  <http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/Publicationspolicyandguidance/Browsable/DH_4867894>  <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216856/CYP-Long-Term-Conditions.pdf>  <http://www.nhs.uk/Livewell/Yourchildatschool/Pages/Longtermconditions.aspx>  <http://www.med.umich.edu/yourchild/topics/chronic.htm>  <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/198114/National_Service_Framework_for_Long_Term_Conditions.pd> f  **Journals**  Antonio Pelliccia, MD. Douglas P. Zipes, MD, Barry J. and Maron, MD. Bethesda Conference #36 and the European Society of Cardiology Consensus Recommendations Revisited: A Comparison of U.S. and European Criteria for Eligibility and Disqualification of Competitive Athletes With Cardiovascular Abnormalities. Journal of the American College of Cardiology [Online] Published 2008 Vol. 52, No. 24. Available at: DOI:10.1016/j.jacc.2008.08.055  Allen Hauser W, Rich, Stephen, Ju R-J, Lee. et al. Risk of Recurrent Seizures After Two Unprovoked Seizures. The New England Journal of Medicine. Volume 338 No. 7, 12 Feb 1998  Clarke, RD. et al. Clinical presentation of childhood leukaemia; a systematic review and meta-analysis. Arch Dis Child 2016;101:894-901 Available at: https://www.ncbi.nlm.nih.gov/pubmed/27647842  ESC Report - Cardiovascular pre-participation screening of young competitive athletes for preventions of sudden death: proposal for a common European protocol. European Heart Journal [Online] published 2005 26, 516 -524 Available at: doi:10.1093/eurheartj/ehi108  Horton TM, Steuber CP. Overview of the treatment of acute lymphoblastic leukemia in children and adolescents. Up to date [Online] Published 2018 Available at: https://www.uptodate.com/contents/overview-of-the-treatment-of-acute-lymphoblastic-leukemia-in-children-and-adolescents  Khalil, A, Suff, N, Thilaganathan, B, Hurrell, A, Cooper, D and Carvalho, J S. Brain abnormalities and neurodevelopmental delay in congenital heart disease: systematic review and meta-analysis Ultrasound Obstet Gynecol [Online] 2014; 43: 14–24, Published 10 December 2013 Available from: DOI:10.1002/uog.12526  Morrow J, Russell A, Guthrie E, Parsons L, Robertson I, Waddell R, et al. Malformation risks of antiepileptic drugs in pregnancy: a prospective study from the UK Epilepsy and Pregnancy Register. Journal of Neurology, Neurosurgery and Psychiatry [Online]. 2006 [accessed 2017 Oct 23]; 77: 193-198. Available from doi: 10.1136/jnnp.2005.074203  Pui RD. et al. Pediatric acute lymphoblastic leukemia: where are we going and how do we get there?  Blood [Online] Published 2012 120:1165-1174 Available at: https://www.ncbi.nlm.nih.gov/pubmed/22730540  Scheffer, IE, Berkovic, S, Capovilla, G, Connolly, MB, French, J, Guilhoto, L,. et al. ILAE classification of the epilepsies: Position paper of the ILAE Commission for Classification and Terminology. [Online] 8 March 2017 [access 2017 Oct 23] Available from: doi/10.1111/epi.13709/full#  Shorvon S, Tomson, T. Sudden unexpected death in epilepsy. Lancet [Online]. 2011 [accessed 2017 Oct 23]; 378: 2028-38. Available from DOI:10.1016/S0140-6736(11)60176-1  Sperling, MA. Editor. ISPAD Clinical Practice Consensus Guidelines. All chapters published in Paediatric Diabetes 2014: 15 (Suppl. 20).  Van der Mheen et al. Study Protocol: The CHIP-Family study to improve the psychosocial wellbeing of young children with congenital heart disease and their families: design of a randomized controlled trial. BMC Pediatrics [Online] Published 2018 18:230 Available from: https://doi.org/10.1186/s12887-018-1183-y  Yi, JC. and Syrjala, KL. Overview of cancer survivorship in adolescent and young adults. Up to date [Online] Published 2018 Available at: https://www.uptodate.com/contents/overview-of-cancer-survivorship-in-adolescent-and-young-adults |
| **Assessment tasks** | Essay – critically evaluate the principles of management of long term conditions in children (2,500 words)  (75% weighting)  Poster presentation – present a case to illustrate your knowledge and application of a management plan for a specific long term condition  (25% weighting) |
| **Brief description of module content and/or aims (maximum 80 words)** | This module will enable you to understand multi-disciplinary approaches to managing long term conditions in children and to develop insight into evidence-based practice, in the clinical, social and psychological aspects of management involved in these conditions. The module is clinically focused and non-disease specific. You will develop a critical understanding of the research, policies and practice relating to long term conditions in various organisational contexts and you will have the opportunity to network with professionals from different disciplines and share best practice. |
| **Area examination board to which module relates** | IPGM – Area Examination Board |
| **Module team/authors/coordinator** | Module Leads : Dr Alok Gupta, Consultant Paediatrician, Clinical Director D&G NHS Trust. Dr Tom Ruffles, Academic Paediatrician, BSMS.  Personal Tutor : Dr Kamal Patel, Consultant Paediatrician |
| **Semester offered, where appropriate** | One |
| **Site where delivered** | BSMS, Falmer |
| **Date of approval of this version** | March 2016 |
| **Field for which module is acceptable and status in that field** | Paediatrics, Nursing, Allied Health Professionals |
| **Course(s) for which module is acceptable and status in that course** | PGCert or PGDip or MSc Paediatrics & Child Health Programme  Compulsory module |
| **School home** | IPGM |
| **External examiner** | Dr Jonathan Round, PICU Consultant, Head of London(South) School of Paediatrics, Director of Medical Education St George’s University Hospitals NHS Trust |