Updated November 2009

1) A Constant Fight – the need for accessible and coordinated services for children and adults with hydrocephalus and/or spina bifida. www.asbah.org/report.html


3) Adolescent Transition Care. Guidance for Nursing Staff (July 2004) Available at www.rcn.ac.uk


19) Baker, K.L and Coe, L.M (1993) Growing up with a chronic condition: Transition to young adulthood for the individual with cystic fibrosis. Holistic Nursing Practice, 8(1) 8-15


40) Binks JA., Barden WS., Burke TA & Young NL (2007). What do we really know about the transition to adult-centred health care? A focus on cerebral palsy and spina bifida archives of Physical Medicine and Rehabilitation. 88 (8) 1064-1073


62) Brands, C. Sharma, N. Transitional Medicine: Perspectives and Challenges from the MPPDA Committee on Transitional Care


References on Transition


References on Transition


References on Transition


References on Transition


References on Transition


Reference on Transition

186) Kalwinsky, D. K. (2002). Health care issues as the child with chronic illness transitions to adulthood. Southern Medical Journal, 95(9), 966-967.


References on Transition


221) Logan, S. (1997). In the UK the transition from youth to adulthood of people with cerebral palsy is poorly planned and coordinated. Child: Care, health and development, 23(6), 479-482.


References on Transition


231) McDonagh JE. (2005) Growing up and Moving on. Transition from pediatric to adult care. Pediatric Transplantation . 9 (3) 364-72


234) McDonagh JE. (2007)Transition of Care from paediatric to adult rheumatology. Archives of Disease in Childhood. 92; 802-807


239) McGill, M. (2002). How Do We Organise Smooth, Effective Transfer from Paediatric to Adult Diabetes Care? Hormone Research 20002;57 (suppl 1),66-68. www.karger.com/journals/hre


References on Transition


255) Moving On – Transition from the Children’s Hospital to the Adult world – Spina Bifida Unit Children’s Hospital at Westmead


259) Munro J (2005). The changing state of surgery for adult congenital heart disease. Heart 91;139-140

260) Murphy K (1999) Falling through the cracks: Children with cerebral palsy may find that health care drops dramatically when they reach adolescence www.gillettechildrens.or


References on Transition


References on Transition


References on Transition


315) Robertson LP, Shaw KL, Southwood TR, McDonagh JE (2005). Growing up and Moving On. A multicentre cohort of adolescents with juvenile idiopathic arthritis. A multicentre audit of the transfer of adolescents with juvenile idiopathic arthritis from paediatric to adult centred care. Rheumatology

316) Robertson LP, Shaw KL, Southwood TR, McDonagh JE (2003). An audit of patients with juvenile idiopathic arthritis recently transferred from paediatric to adult rheumatology clinics. Rheumatology 42:96A
References on Transition


320) Rosen DS, Blum RW, Britto M, Sawyer SM, Siegel DM (2003); Society for Adolescent Medicine. Transition to adult health care for adolescents and young adults with chronic conditions: J Adol Health;33:309-311


References on Transition


343) Shaw KL, Southwood TR, McDonagh JE (2004d) What's in a name? Disease knowledge in juvenile idiopathic arthritis (JIA). Arch Dis Child 89(suppl 1): A44


References on Transition


357) Smith JA. (1996) Beyond the divide between cognition and discourse: using interpretive phenomenological analysis in health psychology. Psychol Health 11:261-71


References on Transition


374) Straatman, LP (2000) Transition to adult care in adolescents with cardiac disease. Perspectives in Cardiology, 16, 30-37


References on Transition

391) Thetford, A. (1999) Transition of Spinal Dysfunction Patients from Princess Margaret Hospital for Children to Adult Services (unpublished)


397) Transition to independence: http://enabledonline.com


408) Videntin, K. towards the development of a model of diabetes care for young adults with type 1 diabetes who are making the transition from children's to adult diabetes health services (2003). Royal District Nursing Service Research Unit, South Australia. www.rdns.net.au
References on Transition


412) Viner R. (2008) Transition of care from paediatric to adult services: one part of improved health services for adolescents. Archives of Disease in Childhood 93, 160-163


References on Transition


441) Wren, C and O'Sullivan J (2001) survival with Congenital heart disease and need for follow up in adult life. Heart;85; 438-443


References on Transition


Websites

Australian Websites

www.rch.org.au/transition
www.diabeteskidsandteens.com.au
www.reachout.com.au
www.chronicillness.org.au
www.kidshelp.com.au
www.aihw.gov.au
www.tribalwell
www.healthinsite.com.au
www.realitycheck.org.au
www.siblingsaustralia.org.au

International Websites

http://hctransitions.ichp.edu/resources.html
http://www.bhiva.org/chiva/protocols/adolescent.html
Washington State Adolescent Transition Resource Notebook; http://depts.washington.edu/healthtr/notebook/content.html
www.AbilityOnline.org
www.diabetes.org.uk/update/autumn01/onup.htm
www.nephronline.org/management/adolescents2.asp
www.nyln.org
www.bc.ca/youthhealth/transition.asp
www.jrf.rog.uk
http://internet.dssc.uic.edu/dsccroot/parents/transition.asp
www.teenagehealthfreak.com
www.doctissimo.fr
www.ciao.ch
www.teenhealthfx.com
www.goaskalice.columbia.edu
www.childrenfirst.nhs.uk
www.need2know.co.uk
www.connexions.gov.uk
www.skill.co.uk (UK based site addressing vocational issues for young people with disabilities)
References on Transition

http://www.abilityonline.org/public/default.htm Ability on line – A free internet community where kids with disabilities or illness can meet role models, mentors and friends.


http://www.sickkids.ca/kidscancope/default.asp Adaptation to Childhood Chronic Illness – The Hospital for Sick Children

http://depts.washington.edu/healthtr/ A health and transition resource for adolescents with special health care needs, chronic illnesses, physical or developmental disabilities

http://www.telability.org - A web-based, interdisciplinary telehealth program operating in North Carolina that is designed to enhance the lives of children with disabilities.

http://www.wowusa.com Winners on Wheels, empowers youth with disabilities in wheelchairs to increase personal achievement.

http://www.acc.org/clinical/bethesda/beth32/dirlIndex.htm

www.childrens-heart-fed.org.uk/workshop%20transition.htm American College of Cardiology, Proceedings of the 32nd Conference Care of the Adult with Congenital Heart Disease.

http://www.achaheart.org Adult Congenital Heart Association

Institute of child Health Great Ormond Street: Transition from paediatric to adult cystic fibrosis services

www.ich.ucl.ac.uk/factsheets/services/cf_transition

www.cysticfibrosismedicine.com

Website: University of Washington PKU Clinic, Seattle

http://depts.washington.edu/pku/pro_info/protocols/transition.htm

The Arthritis Research Campaign (www.arc.org.uk)

Children's Chronic Arthritis Association (www.ccaa.org.uk)

Lady Hoare Trust for physically disabled children, (www.ladyhoaretrust.org.uk)

Young Arthritis Care (www.arthritiscare.org.uk)


Association for Spina Bifida and Hydrocephalus (2003) A constant fight: the need for accessible and coordinated services for children and adults with hydrocephalus and / or spina bifida

www.asbah.org/report.html