

**1. BRAIN INJURY:**

Simpson, G. (2003). You and Me. An Education Program About Sex and Sexuality After a Traumatic Brain Injury. *Brain Injury Rehabilitation Unit*, South Western Sydney Area Health Service, Sydney.

Simpson, G. Simons, M. and McFadyen M. (2002). 'The challenges of a hidden disability: Social work practice in the field of traumatic brain injury. *Australian Social Work*, 55 (1), 24-36.

Shepherd, B., Strettle., B. (1999). *Getting It All Together. A Kit that Promotes Independence in Daily Living When You Have a Brain Injury*. Brain Injury Rehabilitation Unit, South Western Sydney Area Health Service, Sydney.

2. CARDIAC:

Betz, CL. Adolescents in transition of adult care: why the concern? *Nursing Clinics of North America* December 2004;39(4):681-713.

Bjornsen, KD. Health care transition in congenital heart disease: The providers' view point. *Nursing Clinics of North America* December 2004;39(4):715-726.

British Cardiac Society (2002) Grown-up congenital heart (GUCH) disease: current needs and provision of service for adolescents and adults with congenital heart disease. *Heart*; 88, 1-14

Canobbio, MM (2001) Health care issues facing adolescents with congenital heart disease. *Journal of Pediatric Nursing*, 16, 363-370

Canobbio MM. and Higgins, S. Transitional care issues for the adolescent with congenital heart disease. *Nursing Clinics of North America* December 2004;39 (4):xiii-xiv.

Dore A, de Guise P, and Mercier LA (2002) Transition of care to adult congenital heart centres: What do patients know about their heart condition? *Can J Cardiology*, 18(Feb 2), 141-6

Higgins, SS and Tong, E. (2003) Transitioning adolescents with congenital heart disease into adult health care. *Prog Cardiovasc Nurs*, 18(2), 93-8

Fernandes SM, Landzberg MJ. (2004) Transitioning the young adult with congenital heart disease for life-long medical care. *Pediatr Clin N Am* ; 51: 1739-1748.

McGrath, K. A., and Truesdell, S. C. Employability and career counseling for adolescent and adults with congenital heart disease. *Nursing Clinics of North America*. June 1994; 29(2):319-330.

Moons, P., De Volver, E., Budts, W., De Greest, S., Elen, J., Waeytens, K., and Gewilling, M. What do adult patients with congenital heart disease know about their disease, treatment, and prevention of complications? A call for structured patient education. *Heart* 2001;86:74-80.

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

Nieminen, H., Sairanen, H., Tikanoja, T., Leskinen, M., Ekblad, H., Galambosi, P., & Jokinen, E. (2003) Long-term results of pediatric cardiac surgery in Finland: Education, employment marital status, and parenthood. *Pediatrics*;112:1345-1350.

Reid, G. McCrindle, B, Ritvo,P and Webb, GD. (2004) Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. *Pediatrics* Vol 113 (3) pp e197-e205.

Reid, GJ, Irvine, MJ, McCrindle, BW, Sananes, R, Ritvo, PG, Sui, SC & Webb, CD (2004) Prevalance and correlates of successful transfer from pediatric to adult health care among a cohort.Taskforce on the management of grown up congenital heart disease (2003) *European Heart Journal*/Vol 24;11, 1035-1084

Reid, G.J., Irvine, M.J., McCrindle, B.W., Sananes, R., Ritvo, P.G., Siu, S.C., & Webb, G.D. (2004) Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. *Pediatrics*;113(3):e197-e205. <http://www.pediatrics.org/cgi/conent/full/113/3/e205>

Sparacino, PSA, Tong, EM, Messias, DKH, Foote, D, Chesla, CA & Gilliss, CL (1997) The delemmas of parents of adolescents and young adults with congenital heart disease. *Heart & Lung: Journal of Acute and Critical Care*, 26, 187-195

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

The Task Force on the management of grown up congenital heart disease of the European Society of Cardiology.(2003) *European Heart Journal* ;24:1035-1084.

Task Force 2: Special health care needs of adults with congenital heart disease (2001) *Journal of the American College of Cardiology* 37(5):1176-1183.

Task Force 4: Organization and delivery systems for adults with congenital heart disease.(2001) *Journal of The American College of Cardiology* ;37(5):1187-1193.

Task Force 5: Adults with congenital heart disease: Access to care. (2001) *Journal of the American College of Cardiology* ;37(5):1193-1198.

Tong, EM., Kools, SK.(2004) Health care transition for adolescents with congenital heart disease: patient and family perspectives. *Nursing Clinics of North America*, December: 39(4):727-740.

Van Deyk, K., Moons, P., Gewillig, M., & Budts, W. (2004) Educational and behavioral issues in transitioning from pediatric cardiology to adult-centered health care. *Nursing Clinics of North America* December, 39(4):755-768.

Webb G, D. (2003) Challenges in the care of adult patients with congenital heart disease. *Heart* 89, 465-469

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

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.acc.org/clinical/bethesda/beth32/dirIndex.htm>

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

Congenital Heart Information Network – International Organization <http://www.tchin.org>

3. CHRONIC DISEASE MANAGEMENT (CDM):

Adolescent Medicine Committee, Canadian Paediatric Society (1994) Care of the chronically ill adolescent, *Canadian Journal of Paediatrics* 1(4):124-126.

Betz, C.L., (1998), Facilitating the Transition of Adolescents with Chronic Conditions from Pediatric to Adult health Care and Community Settings, in *Issues Comp Pediatric Nursing* 21:97-115

Blum, R, Garell, D, Hodgman, C, Jorrisen, T, Okinow, N, Orr, D, and Slap, G (1993) Transition from Child-Centered to Adult Health-Care Systems for Adolescents with Chronic Conditions, in *Journal of Adolescent Health* 14:570-576

Callahan, S. Todd, Keenan, Peter and Winitzer, Rebecca F. (2001) Transition from pediatric to adult-oriented health care: A challenge for patients with Chronic Disease, in *Current Opinion in Pediatrics*, Lippincott Williams and Wilkins, Inc.

4. CYSTIC FIBROSIS:

Anderson, DL, Flume, PA, Hardy, KK & Gray, S (2002) Transition programs in cystic fibrosis centers: Perceptions of patients. *Pediatric Pulmonology*, 33, 327-331

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

Borowitz, D. (1998) Cystic Fibrosis Extends CF Adult Care Program. *Commitment – Publication of the CF Foundation*

Boyle, M., Farukhi, Z. and Nowisky, M. (2001). Strategies for Improving Transition to Adult Cystic Fibrosis Care, Based on Patient and Parent Views. *Paediatric Pulmonology*, 32:428-436.

Brand, C and Sharma, N. Transitional Medicine: Perspectives and Challenges form the MPPDA Committee on Transitional Care

Brumfield K, Lansbury, G.(2004) Experiences of adolescents with cystic fibrosis during their transition from paediatric to adult health care: a quantitative study of young Australian adults. *Disability Rehabilitation*, 18;26 (4) 223-34

- Burker EJ, Carels RA, Thompson LF, Rodgers L, Egan T. Quality of life in patients awaiting lung transplant: cystic fibrosis versus other end stage lung diseases. *Pediatric Pulmonology* 2000;30:453-460
- Cappelli, M. MacDonald, N.E and McGrath, P.J (1989) Assessment of readiness for transfer to adult care for adolescents with cystic fibrosis. *Children's Health Care*, 18 (4) 218-24
- Cowlard, J (2003) Cystic fibrosis: Transition from paediatric to adult care. *Nurs Stand*, 18(4), 39-41
- Durst CL, Horn MV, MacLaughlin EF, Bowmand CM, Starnes VA, Woo MS. Psychosocial responses of adolescent cystic fibrosis patients to lung transplantation. *Pediatr Transplantation* 2001;5:27-31
- Flume, PA, Anderson, DL, Hardy, KR, & Gray, S (2001) Transition programs in cystic fibrosis centers: Perceptions of pediatric and adult program directors. *Pediatric Pulmonology*, 31, 443-450
- Flume, PA, Taylor, LA, Anderson, DL, Gray, S & Turner, D (2004) Transition programs in cystic fibrosis centers: Perceptions of team members. *Pediatric Pulmonology*, 37(1), 1-3
- Great Ormond Street website- information for families on Transition from paediatric to adult cystic fibrosis services
- Jackson R & Pencharz PB (2003) Transition of care between paediatric and adult gastroenterology. Cystic fibrosis. *Best Pract Res Clin Gastroenterol*, 17(2), 213-35
- Institute of child Health Great Ormond Street: Transition from paediatric to adult cystic fibrosis services www.ich.ucl.ac.uk/factsheets/services/cf_transition
- Landau, L (1995) Cystic fibrosis: Transition from paediatric to adult physician's care. *Thorax*, 1995
- Madge, S. Byron, M. (2002) A model for Transition from Paediatric to Adult Care in Cystic Fibrosis. *Journal of Pediatric Nursing*, Vol 17, no.4 283 - 288
- McDonagh JE. (2005) Growing up and Moving on. Transition from pediatric to adult care. *Pediatric Transplantation* (in press)
- McDonagh JE, Kelly DA. Transitioning care of the pediatric recipient to adult care-givers. *Ped Clin N Am* 2003;50:1561-1584
- Nasr, SZ, Campbell, C and Howatt, W (1992) Transition program from pediatric to adult care for cystic fibrosis patients. *Journal of Adolescent Health* 1992 Dec;13 (8): 682-5
- Palys, BL (1994) Transitioning: On becoming an adult with CF. *International Association of Cystic Fibrosis Newsletter* 36,3-6
- Radley-Smith R, Wray J.(2004) Depression in pediatric patients before and 1 year after heart or heart-lung transplantation. *J Heart Lung Transplant* 3:1103-10.

Steinkamp G, Ullrich G, Muller C, Fabel H & von der Hardt H (2001) Transition of adult patients with cystic fibrosis from paediatric to adult care--the patients' perspective before and after start-up of an adult clinic. *Eur J Med Res.*, 28;6(2), 85-92

Stevenson, CJ, Pharoah, POD & Stevenson, R (1997) Cerebral palsy—the transition from youth to adulthood. *Developmental Medicine & Child Neurology*, 39, 226-342

www.cysticfibrosismedicine.com

5. DEVELOPMENTAL DISABILITY TRANSITION REFERENCES:

Beange H.P (1996) Caring for a vulnerable population. *Medical Journal of Australia* 164:159-160

Halpern, A.S. (1989). 'A Systemic Approach to Transition Programming for Adolescents and Young Adults with Disabilities'. *Australian and New Zealand Journal of Developmental Disabilities*, 15 (1), 1-13.

Kastner, T. (1991) Who cares for the young adult with mental retardation? *Developmental and Behavioural Pediatrics*. 12 (3) 196-98

O'Connell, B., Bailey, S., Pearce,J. (2003). Straddling the Pathway from Paediatrician to Mainstream Health Care: Transition Issues Experienced in Disability Care. *Australian Journal of Rural Health*. Vol 11, (2) 57.

Riches, V.C., Parmenter, T.R., Robertson, G. (1996). *Youth With Disabilities in Transition From School to Community. Report of a follow –along of students with disabilities involved in the New South Wales transition initiative 1989 – 1994*. The Unit for Community Integration Studies, School of Education, Macquarie University, Sydney.

Watson, D. Townsley,R and Abbottt, D (2002) Exploring multi-agency working in services to disables children with complex healthcare needs and their families *Journal of Clinical Nursing* 11: 367-375

www.ddhealthinfo.org

6. DIABETES / OTHER ENDOCRINE:

Anderson, BJ & Wolpert, HA (2004) A developmental perspective on the challenges of diabetes education and care during the young adult period. *Patient Education and Counseling*, 53, 347-52

Beck, MJ, Evans, BJ, Quarry-Horn, JL, & Kerrigan, JR (2002) Type 2 Diabetes Mellitus: Issues for the medical care of pediatric and adult patients. *Southern Medical Journal*, 95, 992-1000

Clayton PE, Cuneo RC, Juul A, Monson JP, Shalet SM, Tauber M. (2005) Consensus statement on the management of the GH-treated adolescent in the transition to adult care. *Eur J Endocrinology*,152:165-170.

Diabetes Update Autumn 2001 : Moving on up.

Eisrer C, Flynn, Green E Havermans T, Kirby R Sandeman D and Tooke JE (1993) coming of Age with diabetes: patients views of a clinic for under 25 year olds. *Diabetic Medicine*, 10 285-289.

Fleming E, Carter, B and Gillibrand W (2002). The transition of adolescents with diabetes from the children's health care service into the adult health care service: a review of the literature. *Journal of Clinical Nursing*, 11 560-567.

Frank, M (1995) Rights to passage: Transition from paediatric to adult diabetes care. *Diabetes Care*, 16(3) 85-9

Holmes Walker, J. and Llewellyn,A. (2003) Transition Diabetes Project, Western Sydney Area Health Service. Baxter Awards . *NSW Department of Health intranet site*

Hope, M. (1996) Adolescent Transition issue in Chronic Illness. Presented at annual Scientific Conference- Stomal Therapy Melbourne.

Kyngas H and Barlow J (1995) diabetes: an adolescent perspective. *Journal of Advanced Nursing* 22, 941-947.

Kipps, S., Bahu, T., Ong, K., Ackland, FM., Brown, RS., Fox, CT., Griffin, NK., Knight, AH., Mann, NP., Neil, HAW., Simpson, H., Edge, JA., & Dunger, DB. (2002) Current methods of transfer of young people with type 1 diabetes to adult services. *Diabetic Medicine*, 19:649-654.

National Diabetes Strategy Group. Australian Clinical Practice Guidelines: Diabetes in Children and Adolescents. (See their website)

Orr, DP, Fineberg, NS., & Gray, DL.(1996) Glycemic control and transfer of health care among adolescents with insulin dependent diabetes mellitus. *Journal of Adolescent Health* 18:44-47.

Pacaud, D., & Yale, J-F. (2005) Exploring a black hole: Transition from pediatric to adult care services for youth with diabetes. *Pediatrics and Child Health* ,10(1):31-34.

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

Rasmussen, B, Wellard, S & Nankervis, A (2001) Consumer issues in navigating health care services for type I diabetes. *Journal of Clinical Nursing*, Vol 10, 628-34

Rewers, M., LaPorte, RE., King, H., & Tuomilehto, J. Trends in the prevalence and incidence of diabetes: Insuline-dependent diabetes mellitus in childhood. *World Health Statistics Quarterly* 1988;41:179-189.

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

Williams, C. (2000). Doing Health, doing gender: teenagers, diabetes and asthma. *Social Science and Medicine* 50, 387-396.

Volta, C, Luppino, T, Street, ME & Bernasconi, S (2003) Transition from pediatric to adult care of children with chronic endocrine diseases: A survey on the current modalities in Italy. *Journal of Endocrinological Investigation*, 26, 157-162

7. EPILEPSY / COMPLEX NEUROLOGY:

Appleton, RE, Chadwick, D & Sweeny, A (1997) Managing the teenager with epilepsy: Paediatric to adult care. *Seizure*, 6, 27-30

Epilepsy Centre www.hoaghospital.org/epilepsycenter/ Working Together to Ease the Adolescent Transition

Reeve, D.K & Lincoln, (2002) N.B Coping with the challenge of transition in older adolescents with epilepsy. *Seizure* vol 11: 33-30

Tuffrey, C & Pearce AJ (2003) Transition from paediatric to adult medical services for young people with chronic neurological problems. *Neurol Neurosurg Psychiatry*, 74(8), 1011-3

8. GASTROENTEROLOGY:

Baldassano R, Ferry G, Griffiths A, Mack D, Markowitz J, Winter H. (2002) Transition of the patient with inflammatory bowel disease from pediatric to adult care: Recommendations of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition. *J Pediatr Gastroenterol Nutr*, 34:245-8.

David, TJ (2001) Transition from paediatric clinic to the adult service. *Journal of the Royal Society of Medicine*, 94, 373-374

Davies, IH & Jenkins, HR (2003) Transition clinics for adolescents with chronic gastrointestinal disease in the UK and Ireland. *J Pediatr Gastroenterol Nutr*, 36(4), 505-6

Otley, A., Smith, C., Nicholas, D., Munk, M., Avolio, J., Sherman, PL., & Griffiths, AM. (2002) The IMPACT questionnaire: A valid measure of health-related quality of life in Pediatric inflammatory bowel disease. *Journal of Pediatric Gastroenterology and Nutrition*, 35:557-563.

Pinzon, JL., Jacobson, K., & Reiss, J. (2004) Say goodbye and say hello: The transition from pediatric to adult gastroenterology. *Canadian Journal of Gastroenterology*, 18(12):735-742.

Recommendations of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition. (2002) Transition of the patient with Inflammatory Bowel disease from Pediatric to Adult Care: Medical Position Statement. *Journal of Pediatric Gastroenterology and Nutrition*

Thomson, A. (2004). 'Position Statement: Gastroenterology Patients in Transition from Childhood to Adulthood'. http://omge.org/guidelines/statment02/s_data2_en.htm

9. HAEMATOLOGY:

Belling, L, Harrop, M, Kocik, S, Obstein, L, Standish, D, Vlasich, W., & Zappa, S (2003) Transition guidelines for people with bleeding disorders. *HEMAware*, 8 (4), 88-95

Britto MT, Garrett JM, Dugliss MAJ et al.(1998) Risky behaviours in teens with cystic fibrosis or sickle cell disease: a multicentre study. *Pediatrics* , 101:250-4

Britto MT, Garrett JM, Dugliss MAJ et al.(1999) Preventive services received by adolescents with cystic fibrosis and sickle cell disease. *Arch Pediatr Adol Med*, 153: 27-32.

Burlew K, Telfair J, Colangelo L, & Wright EC. (2000) Factors that influence adolescent adaptation to sickle cell disease. *J Pediatr Psychol*, 25, 287-299

Flume PA, Anderson DL, Hardy KK, Gray S. Transition programs in cystic fibrosis centers: perceptions of pediatric and adult program directors.. *Pediatr Pulmonol* 2001;31:443-450.

Francis, D (1995) Bridging the gaps: Adolescents with clotting disorders transition to adult care. *Nursing Network/Psychosocial News*. (Summer), 10-11

Francis, D. (1995) Bridging the Gaps: Adolescents with clotting disorders transition to adult care. *Nursing Network/Psychosocial News*, Summer 10-11

Hauser E, Dorn L. (1999). Transitioning Adolescents with sickle cell disease to adult-centered care. *Pediatric Nursing*, 25 (5), 479-488.

Telfair, J, Ehiri, JE, Loosier, PS & Baskin, ML (2004) Transition to adult care for adolescents with sickle cell disease: Results of a national survey. *International Journal of Adolescent Medicine and Health*, 16, 47-64

Telfair J, Myers J, Drezner S.(1994) Transfer as a component of the transition of adolescents with sickle cell disease to adult care: adolescent, adult and parent perspectives. *J Adolesc Health*, 15: 558-565.

Telfair J, Alexander LR, Loosier PS, Alleman-Velez PL, Simmons J.(2004) Providers' perspectives and beliefs regarding transition to adult care for adolescents with sickle cell disease. *J Health Care Poor Underserved*, 15: 443-461.

Telfair J, Ehiri JE, Loosier PS, Baskin ML (2004). Transition to adult care for adolescents with sickle cell disease – results of a national survey. *Int J Adol Med Health*, 16: 47-64.

Transition guidelines for People with Bleeding disorders. *National Hemophilia Foundation*. www.hemophilia.org

Wojciechowski, E, Hurtig, A & Dorn, L (2002) A natural history study of adolescents and young adults with sickle cell disease as they transfer to adult care: A need for case management services. *Journal of Pediatric Nursing*, 17, 18-27

10. HIV / AIDS:

Lyll, H. (2004) Growing up, Gaining Independence. Principles for Transition of HIV Care. www.bhiva.org/chiva/protocols/adolescent.html

Miles, K, Edwards, S & Clapson, M (2004) Transition from paediatric to adult services: Experiences of HIV-positive adolescents. *AIDS Care*, 16(3), 305-14

11. INBORN ERRORS OF METABOLISM:

Enns, GM & Packman, W (2002) The adolescent with an inborn error of metabolism: medical issues and transition to adulthood. *Adolescent Medicine*, 13(2), 315-29, vii

Website: University of Washington PKU Clinic, Seattle
http://depts.washington.edu/pku/pro_info/protocols/transition.htm

12. MENTAL HEALTH

Crago,A., Wigg,C.and Stacey,K.2004. 'First you have to see them: Youth friendly practice in mental health work' in *Youth Studies Australia*, vol.23,no.2, p.39

Davis, M.2003, Addressing the needs of youth in transition to adulthood in *Administration and Policy in Mental Health*, vol.30, no.6, July2003,p 496

Research and Training Centre on Family Support and Children's Mental Health 2006. Making the most of transitions: The challenges for children and adolescents with mental health difficulties www.rtc.pdx.edu/pgFeatureddiscussions31.php

Haliburn,J.M 1993 The forgotten in-betweens: middle to late adolescents with psychiatric disorders in *Youth Studies Australia*, vol 12 (3) pp47-48

13. NEUROLOGY: Neurology (Cerebral Palsy, spina bifida)

Bax MC, Smyth DP, Thomas AP (1998). Health care of physically handicapped young adults. *Br Med J journal*, 296: 1153-5.

Beresford B.(2004) On the road to nowhere? Young disabled people and transition. *Child: Care, Health and Development* , 30:581-587.

Blum RW, Resnick MD, Nelson R, St Germaine A. (1991) Family and peer issues among adolescents with spina bifida and cerebral palsy. *Pediatrics*, 88: 280-285.

Cathels BA, Reddihough D.(1993) The health care of young adults with cerebral palsy. *Med J Australia* 159:444-6.

Morgan DJR, Blackburn M, Bax M. (1005) Adults with spina bifida and/or hydrocephalus. *Postgrad Med Journal*, 71: 17-21.

Peterson, P.M., Rauen, K.K., Brown, J., & Cole, J. (1994) Spina bifida: The transition into adulthood begins in infancy. *Rehabilitation Nursing*, 19(4):229-237.

Rogers, AS., Miller, S., Murphy, DA., Tanney, M., & Fortune, T.(2001) The TREAT (Therapeutic Regimens Enhancing Adherence in Teens) program: Theory and preliminary results. *Journal of Adolescent Health*, 29S:30-38.

Sawyer SM, Roberts KV (1999). Sexual and reproductive health in young people with spina bifida. *Dev Med Child Neurol* 41:671-5.

Sawyer SM, Collins, Bryan D, Brown D, Hope MA, Bowes G. Young people with spina bifida: transfer from pediatric to adult health care. *J Paed Child Health* 1998;34:414-7.

Stevenson CJ, Pharoah POD, Stevenson R.(1997) Cerebral palsy - the transition from youth to adulthood. *Dev Med Child Neurol*, 39: 336-42.

Willey, C., Redding, C., Stafford, J, et al. (2000) Stages of change for adherence with medication regimens for chronic disease: Development and validation of a measure. *Clin Ther*, 22:858-871.

14. ONCOLOGY:

Armstrong, F.D. (1992). Psychosocial intervention in pediatric cancer: A strategy for prevention of long-term problems. In T.M. Field, P.M. McCabe, & N. Schneiderman, Eds., *Stress and coping in infancy and childhood* (pp. 197-218).

Battista, E.M. (1986). Educational needs of the adolescent with cancer and his family. *Seminars in Oncology Nursing*, 2, 123-125.

Bleyer WA. Cancer in older adolescents and young adults: epidemiology, diagnosis, treatment, survival, and importance of clinical trials. *Med Pediatr Oncol* 2002; 38: 1-10.

Brown, R.T., & Madan-Swain, A. (1993). Cognitive, neuropsychological, and academic sequelae in children with leukemia. *Journal of Learning Disabilities*, 26, 74-90.

Castellino, S & Hudson, MM (2002) Health issues in survivors of childhood cancer. *Southern Medical Journal*, 95, 977-984

Cole CH. Doing better with cancer in adolescents and young adults [editorial]. *Med J Aust* 2004; 180: 52.

Duffner, P.K., Cohen, M.E., & Freeman, A.A. (1985). Pediatric brain tumors: An overview. *Cancer Journal for Clinicians*, 35, 287-301.

Ewing JE. Are we doing enough for young people with chronic illness? *Aust N Z J Public Health* 2003; 27: 560.

Granowetter, L. (1994). Pediatric oncology: A medical overview. In D.J. Bearison & R.K. Mulhern (Eds.), *Pediatric psychooncology: Psychological perspectives on children with cancer* (pp. 9-34).

Horowitz, M.E., & Pizzo, P.A. (1990). Cancer in the child infected with human immunodeficiency virus. *Journal of Pediatrics*, 116, 730-731.

- Katz, E.R., Dolgin, M.J., & Varni, J.W. (1990). Cancer in children and adolescents. In A.M. Gross & R.S. Drabman (Eds.), *Handbook of clinical behavioral pediatrics: Applied clinical psychology* (pp.129-146).
- Kazak, A.E. (1994). Implications of survival: Pediatric oncology patients and their families. In D.J. Bearison & R.K. Mulhern (Eds.), *Pediatric psychooncology: Psychological perspectives on children with cancer* (pp. 171-193).
- Kazak, A.E., Christakis, D., Alderfer, M., & Coiro, M.J. (1994). Young adolescent cancer survivors and their parents: Adjustment, learning problems, and gender. *Journal of Family Psychology*, 8, 74-84.
- Konsler, GK & Jones, GR (1993) Transition issues for survivors of childhood cancer and their health care providers. *Cancer Practice*. 1(4): 319-324
- LaGreca, A.M. (1990). Social consequences of pediatric conditions: Fertile area for future investigation and intervention. *Journal of Pediatric Psychology*, 15, 285-307.
- Meadows, A., & Silber, J. (1985). Delayed consequences of therapy for childhood cancer. *Cancer Journal for Clinicians*, 35, 271-286.
- Michelagnoli MP, Pritchard J, Phillips MB. Adolescent oncology — a homeland for the “lost tribe”. *Eur J Cancer* 2003; 39: 2571-2786.
- Mitchell AE, Scarcella DL, Rigutto GL, et al. Cancer in adolescents and young adults: treatment and outcome in Victoria. *Med J Aust* 2004; 180: 59-62.
- Morris J. (1999) *Hurling into a Void*. Brighton. Pavilion Publishing/Joseph Rowntree Foundation.
- Phipps, S. (1994). Bone marrow transplantation. In D.J. Bearison & R.K. Mulhern (Eds.), *Pediatric psychooncology: Psychological perspectives on children with cancer* (pp. 143-170).
- Stevens, M.M., & Dunsmore, J.C. (1996). Adolescents who are living with a life-threatening illness. In C.A. Corr & D.E. Balk (Eds.), *Handbook of adolescent death and bereavement* (pp. 107-135).
- Pruyn, J.F., De Groot, A., Koot, H.M., Hahlen, K., & Verhulst, F.C. (1995). Late psychosocial consequences for parents of children who survived cancer. *Journal of Pediatric Psychology*, 20 567-586.
- Whelan J. Where should teenagers with cancer be treated? *Eur J Cancer* 2003; 39: 2573-2578.
- Zebrack, BJ, Eshelman, DA, Hudson, MM, Mertens, AC, Cotter, KL, Foster, BM, Loftis, L, Sozio, M & Oeffinger, KC (2004) Health care for childhood cancer survivors: Insights and perspectives from a Delphi panel of young adult survivors of childhood cancer. *Cancer*, 100, 843-50

Teenagers and young adults with cancer – a national group for professionals
www.tyac.org.uk

15. RENAL:

Cameron, JS (1985) The continued care of pediatric patients with renal disease into adult life. *American Journal of Kidney Disease*. 6(2): 91-95

Cameron JS. The continued care of children with renal disease into adult life. *Pediatr Nephrol* 2001;16: 680-685

Ehrich JHH, Rizzoni G, Broyer M et al.(1992) Rehabilitation of young adults during renal replacement therapy in Europe 2. Schooling, employment and social situation. *Nephrol Dial Transplant* 7: 573-8.

McDonagh JE.(2000) The Adolescent Challenge. *Nephrol Dial Transplant* , 15: 1761-1765

Morton MJ, Reynolds JM, Garralda ME, Postlethwaite RJ, Goh D.(1994) Psychiatric adjustment in end-stage renal disease. A follow-up study of former paediatric patients. *J Psychosomatic Res*, 38: 293-303.

Myers, PS (2002) Transitioning an adolescent dialysis patient to adult health care. *Nephrol Nurs J*, 29, 375-6

Reynolds JM, Morton MJ, Garralda ME, Postlethwaite RJ, Goh D.(1993) Psychosocial adjustment of adult survivors of a paediatric dialysis and transplant programme. *Arch Dis Child*,68: 104-10.

Watson AR, Shooter M.(1996) Transitioning adolescents from paediatric to adult dialysis units. *Advances Peritoneal Dialysis*,12: 176-178.

Watson AR.(2001) Non-compliance and transfer from paediatric to adult transplant unit. *Pediatr Nephrol* , 14: 469-472.

Watson AR.(2005) Problems and pitfalls of transition from paediatric to adult renal care *Pediatr Nephrol*, 20:113-117.

16. RHEUMATOLOGY:

Barlow JH, Shaw KL, Harrison K (1999). Consulting the "experts": children's and parents' perceptions of psycho-educational interventions in the context of juvenile chronic arthritis. *Health Education Research* 14:597-610

Beresford BA, Sloper P (2003). Chronically ill adolescents' experiences of communicating with doctors: a qualitative study. *J Adol Health* 33:172-179

Berry SL, Hayford JR, Ross CK et al (1993) Conceptions of illness by children with juvenile rheumatoid arthritis: a cognitive developmental approach. *J Pediatr Psychol* 18: 83-97.

Britto MT, Rosenthal SL, Taylor J, Passo MH (2000). Improving rheumatologists screening for alcohol use and sexual activity. *Arch Pediatr Adolesc Med* 154: 478-48

Carroll G, Massarelli E, Opzoomer A, Pekeles G, Pedneault M, Frappier JY, Onetto N (1983). Adolescents with chronic disease: are they receiving comprehensive health care? *J Adol Health Care* 17: 32-6.

Chamberlain MA, Rooney CM (1996). Young adults with arthritis: meeting their transitional needs. *Br J Rheumatol* 35: 84-90.

Chira, P. and Sandborg C.(2003)Adolescent Rheumatology transitional care:steps to bringing health policy into practice *Rheumatology Vol 43, 6;*

Forbes A, While A, Ullman R et al (2002). A multi-method review to identify components of practice which may promote continuity in the transition from child to adult care for young people with chronic illness or disability. National Co-ordinating Centre for NHS Service Delivery and Organisation R & D.

Foster HE, Marshall N, Myers A, Dunkley P, Griffiths ID (2003). Outcome in adults with juvenile idiopathic arthritis. *Arthritis Rheum* 48:767-775.

Hackett J, Johnson B (2001). Evaluation of an independence break for teenagers with rheumatic disease. *Ann Rheum Dis* 60 (Suppl. 52):198.

Konkol L, Lineberry J, Gottlieb J, Shelby PE, Miller JJ, Lorig K (1989). Impact of juvenile arthritis on families. An educational assessment *Arthritis Care Res* 2:40-48.

Leak, A.M. (2000) Improving adolescent rheumatology services in the UK. *Rheumatology* 39; 575-579

McDonagh JE, Southwood TR, Shaw KL, on behalf of the British Paediatric Rheumatology Group (2004). Unmet educational needs of rheumatology health professionals in adolescent health and transitional care. *Rheumatology* 43:737-43.

McDonagh JE, Southwood TR, Shaw KL on behalf of the British Paediatric and Adolescent Rheumatology Society (2005) Growing up and moving on in rheumatology: disease knowledge in a multicentre cohort of adolescents with Juvenile Idiopathic Arthritis (JIA). *Arch Dis Child* (abstract, in press)

Minden K, Niewerth M, Listing J, Biedermann T, Schontube M, Zink A (2004). Burden and cost of illness in patients with juvenile idiopathic arthritis. *Ann Rheum Dis* 63:836-842.

Nash AA, Britto MT, Lovell DJ, Passo MH, Rosenthal SL (1998). Substance use among adolescents with juvenile rheumatoid arthritis. *Arthritis Care and Res* 11:391-6.

OConnor D, Shaw KL, McDonagh JE (2004). A user perspective of the Rheumatology Adolescent Planner – An aid to transitional care for adolescents with juvenile idiopathic arthritis (JIA). *Rheumatology*;43 (suppl 2):273

Oen K, Malleson PN, Cabral DA, Rosenberg AM, Petty RE, Cheang M (2002). Disease course and outcome of juvenile rheumatoid arthritis in a multicenter cohort. *J Rheumatol* 29:1989-99.

Packham JC, Hall MA (2002a). Long-term follow-up of 246 adults with juvenile idiopathic arthritis: education and employment. *Rheumatology* 41:1436-1439

Packham JC, Hall MA (2002b). Long-term follow-up of 246 adults with juvenile idiopathic: Social function, relationships and sexual activity. *Rheumatol* 41:1440-1443

Paone MC (2000). Setting the Trac – A Resource for Health Care Providers. Children's and Women's Health Centre of British Columbia.

Rettig P, Athreya BH (1991). Adolescents with chronic disease: transition to adult health care. *Arthritis Care Res* 4:174-80.

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

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* (abstract in press)

Shaw KL, Southwood TR, McDonagh JE on behalf of the British Paediatric Rheumatology Group (2004a). Developing a Programme of Transitional Care for Adolescents with Juvenile Idiopathic Arthritis: Results of a Postal Survey *Rheumatology* 43:211-219.

Shaw KL, Southwood TR, McDonagh JE on behalf of the British Paediatric Rheumatology Group (2004b). User perspectives of transitional care for adolescents with juvenile idiopathic arthritis. *Rheumatology* 43:770-78.

Shaw KL, Southwood TR, McDonagh JE on behalf of the British Paediatric Rheumatology Group (2004c). Transitional care for adolescents with juvenile idiopathic arthritis: a Delphi study. *Rheumatology* 43:1000-6

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

Shaw KL, Southwood TR, McDonagh JE (2005a). Growing up and Moving On. A multicentre cohort of adolescents with juvenile idiopathic arthritis. (*Rheumatology* in press)

Shaw KL, Southwood TR, McDonagh JE on behalf of the British Paediatric and Adolescent Rheumatology Society (2005b) Growing up and moving on in rheumatology: transitional care and quality of life in a multicentre cohort of adolescents with Juvenile Idiopathic Arthritis (JIA). *Arch Dis Child* (abstract, in press)

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

Sneed RC, May WL, Stencel CS (2000). Training of pediatricians in care of physical disabilities in children with special health needs: results of a two-state survey of practising pediatricians and national resident training programs. *Pediatrics* 105:554-61.

Steff ME, Shear ES, Levinson JE (1996). Summer camps for juveniles with rheumatic disease: do they make a difference? *Arthritis Care Res* 9:35-41.

Suris JC, Michaud PA, Viner R (2004). The adolescent with a chronic condition. Part 1: developmental issues. *Arch Dis Child* 89:938-942.

Suris JC, Resnick MD, Cassuto N, Blum RW (1996). Sexual behaviour of adolescents with chronic disease and disability. *J Adolesc Health* 19:124-31.

Ullrich G, Mattussek S, Dressler F, Thon A (2002). How do adolescents with juvenile chronic arthritis consider their disease related knowledge, their unmet service needs and the attractiveness of various services? *Eur J Med Res* 7:8-18.

White PH (1997). Success on the road to adulthood. Issues and hurdles for adolescents with disabilities. *Rheum Dis Clin N Am* 23:697-707.

White, PH & Shear, ES (1992) Transition/Job Readiness for adolescents with Juvenile Arthritis and other chronic illness, *Journal of Rheumatology*, 19 ,23

Zack J, Jacobs CP, Keenan PM, et al (2003). Perspectives of patients with cystic fibrosis on preventive counselling and transition to adult care. *Pediatr Pulmonol* 36:376-83.

Websites

- 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)
- CHAT Alliance (2001) Chat 2 parents. CHAT Alliance, UK (www.ccaa.org.uk)

17. SPINA BIFIDA:

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

Blum, R.W, Resnick M, Nelson R and St Germaine A. (1991) Family and peer issues among adolescents with spina bifida and cerebral palsy. *Pediatrics*, 88(2) 280-5

Johnson C and Dorval J. Transitions into Adolescence. *Spina Bifida Association of America Fact Sheet*. <http://www.sbaa.org>

Peterson P.M, Rauen K.K, Brown J and Cole C. (1994) Spina bifida: The transition into adulthood begins in infancy. *Rehabilitation Nursing* 19(4) 229-37

Sawyer S, Collins N, Bryan D, Brown D, Hope M and Bowes G. (1998) Young People with Spina Bifida; Transfer from Paediatric to Adult Health Care. *Journal of Paediatrics and Child Health*, 34 (5) 414-417

Transition to independence: <http://enabledonline.com>

Tuffrey C and Pearce A. (2003) Transition from paediatric to adult medical services for young people with chronic neurological problems. *Journal of Neurology Neurosurgery and Psychiatry* &4: 1011-1013

18. SPINAL:

Anderson CJ, Johnson KA, Klaas SJ, & Vogel LC (1998) Pediatric spinal cord injury: Transition to adulthood. *Journal of Vocational Rehabilitation*, 10, 103-113

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

Vogel LC, Klaas SJ, Lubicky JP, & Anderson CJ (1998) Long-term outcomes and life satisfaction of adults who had pediatric spinal cord injuries. *Archives of Physical Medicine and Rehabilitation*, 79, 1496-1503