



The West Midlands YARN

Young Adult Rheumatology Newsletter

VOLUME 1, ISSUE 2

AUTUMN 2009

Spotlight on the Young Adult Clinic at University Hospital Birmingham



INSIDE THIS ISSUE:

Transition Coordinator Update 2

Training 3

Useful Resources 3

Your Space! 3

The YARN Bookshelf 4

It can be a daunting experience moving from the familiar environment and well-known faces of a paediatric clinic to adult rheumatology services, which is why at Selly Oak Hospital, young people are brought by Marie McGee, Transition Care Co-ordinator at BCH, for Orientation visits. It allows them to view the department and to meet Nurse Specialist Sarah Logan, ahead of their first formal appointment

Each individual is then seen in a dedicated Young Adult Clinic which runs every three months, timed to coincide with College and University breaks. There are many resources available in the

waiting area and members of the Multidisciplinary Team are on hand to deal with any issues.

Dr Elizabeth Rankin has established a Strategic Working Party for the Development of Transitional and Young Adult Care with active members from across many specialities in the Trust, which aims to improve the experience of young people as their care moves from paediatric to adult services at UHB.

Dr Alison Jordan joined the team as an SpR in January 2008, after gaining valuable experience at BCH during her training and is helping to develop Young Adult Services since her appointment as Consultant within the

Trust, in May this year. She also chairs the Paediatric and Adolescent Special Interest Group for the BSR. It would be great to hear about Young Adult Services for Rheumatology in your locality. We would love to turn the spotlight on your unit in our next issue and share your good practice with others, so please do get in touch and tell us what you are doing or planning! Contact Janet, Alison or Marie-details at back.



*You're Welcome quality criteria
Making health services young people friendly*



Pilot of the You're Welcome Self Assessment

Birmingham Children's Hospital is one of 14 acute trusts taking part in a Department of Health national pilot of the You're Welcome Quality Criteria for Young person Friendly Health services in Acute Trusts. A revised toolkit will hopefully be available from early summer 2010

when any acute trust seeing young people can assess themselves and work towards getting "You're Welcome" accreditation. The approval process involves verification panels of young people as well as professionals. For more information, check out the tools on www.dh.gov.uk or contact Janet McDonagh (j.e.mcdonagh@bham.ac.uk).



The 5A Tool For Brief Interventions

Ask
Advise
Assess
Assist
Arrange

Adolescent Transition Coordinator @ 10 months!

The development of my transition role has been very positive over the last 10 months. Working alongside the multi disciplinary team within the rheumatology department at BCH I have started to coordinate the care that the young people receive to prepare them for transition into adult rheumatology services.

The need for early preparation is paramount to the transition process where specific health needs and how they affect the young persons social, psychological, educational, employment and vocational needs can be addressed in a non threatening and supportive manner.

My role involves starting the transition process in general clinic with young people aged around 11/12 (age and developmentally appropriate) where they are given the first of three young person friendly screening tools to encourage information sharing. The young people move up to adolescent clinic around 13/14 (age and developmentally appropriate) where areas such as over-protection, dependence on others, competence and autonomy can be addressed more succinctly within the support offered to parents/carers. Signposting to current, effective agencies and community services is very important as there are obviously limitations to the support that the team can offer.

During the transition process conversations around the actual transfer into adult healthcare should become

more focussed and detailed. It is vitally important that the young person should be involved in developing their transition programme to enhance their sense of control and independence. The young person and their family will also need as much information as possible about adult rheumatology services so that they can make informed choices about their future health care. I have had the opportunity to visit several of the adult units which has been extremely useful to help us prepare young people for their transfer to adult units— many thanks to everyone who has made me so welcome!

Social visits to the identified adult hospital are offered to the young people and their families. Anyone that agrees to a visit is met at the hospital where they can look around the department and meet staff on an informal basis. The feedback I have

had from these includes 'I don't feel so scared now!' (Young Person) This has really helped, I can continue to prepare x so that she feels confident and at ease for her first appointment with the adult doctor (Parent/ Carer).

My role has also covered CAF assessments, family support in the home, state-menting meetings, delivering positive lifestyle events, attending a family support weekend and taking part in a four day breakaway trip for the young people. If you would like any further information please contact me at marie.mcgee@bch.nhs



New booklet for Young People

My Lupus – what I need to know. A Young Person's Guide

A 15 page booklet, specially written for teenagers. A joint LUPUS UK/ Juvenile SLE Group production

dered free from:
Lupus UK, St James House, Eastern Rd, Romford, Essex RM1 3 NH
Tel: 01708 731251
www.lupusuk.org.uk

Copies can be or-

Forthcoming Training Opportunities

11 December 2009
“Adolescent Medicine Comes of Age”
Royal College of Physicians and Surgeons, Glasgow

8 February 2010
Working Systematically with paediatric and Adolescent Health : Practice Based Evidence
Institute of Child Health, London
Wwww.ichevents.com

23rd March 2010
Young People and the Media
Manchester
Wwww.youngpeopleshealth.org.uk



Examples of Useful Resources

National:

Wwww.princes-trust.org.uk

Site of Princes Trust—provides excellent courses for young people in the 16-25 year old age group eg Team, Get Into, and Get Started Programmes —for 16-25 year olds who are unemployed

<http://www.nhs.uk/Lifecheckers/Pages/TeenMarketingMaterials.aspx>

Includes Teen Life Check related posters which can be downloaded in used in clinic/ waiting room areas

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Your Space. We want to hear from YOU!

- Now it is your turn!
- What can we do for you?
- What do you need from us?
- Information?
- Signposting?
- More/less information in the transfer summary?

An adolescent health training session for your team?
Please let us know your ideas as to what you would like us to put in this newsletter, or any particular resources we could potentially help you develop. Please contact Marie, Janet, or Alison and let us know

(details on back page)



Dedicated
Rheumatology
Expert
Adolescent
Multidisciplinary
TEAM



Useful UK Organisations for Health Professionals interested in Adolescent HealthCare

Adolescent Rheumatology Team, www.dreamteam-uk.org

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RCPCH Young People's Health
Special Interest Group
www.yphsig.org.uk

Association for Young People's Health
Www.youngpeopleshealth.org.uk

Training Resources
www.e-lfh.org.uk
www.euteach.com




*****STOP PRESS***STOP PRESS***STOP PRESS*****

Last Month, the Chief Executive of the NHS, David Nicholson, has commissioned Sir Ian Kennedy to explore the cultural obstacles that can stand in the way of sustained improvement in the provision of care for children and young people and specifically highlighted the area of transitional care!

<http://www.dh.gov.uk/en/Healthcare/Children/ChildHealthPromotion/index.htm>

The YARN Book Shelf

 Stinson JN, Tucker L, Huber A et al Surfing for Juvenile Idiopathic Arthritis: Perspectives on Quality and Content of Information on the Internet. *J Rheumatol* 2009 *J Rheumatol*. 2009 Aug;36(8):1755-62. Epub 2009 Jun 16.

 Stinson J, Wilson R, Gill N, Yamada J, Holt J. A systematic review of internet-based self-management interventions for youth with health conditions. *J Pediatric Psychology* 2009;34:495-510.

 Hardoff D, Danziger Y, Reisler G, Stoffman N, Ziv A. Minding the gap: training in adolescent medicine when formal training programmes are not available. *Arch. Dis. Child. Ed. Pract.* 2009;94 157-160

**Read anything interesting recently? If yes—do pass it on.
Plenty of room on the YARN Shelf!!!**