

Transition Task Force

Membership

Dr Paula Bolton-Maggs - Chair	Manchester Royal Infirmary (Adults)
Dr Jonathan Wilde	Birmingham (Adults) resigned March 2011
Dr Mary Mathias	Great Ormond Street, London (Paediatric)
Dr Rachel Rayment	Cardiff
Dr Lishel Horn	Edinburgh (Adults)
Sister Aileen Gibson	Glasgow (Paediatric)
Sister Anna Farrell	Bristol (Paediatric)
Sister Emma Franklin	Bristol (Paediatric)
Anna Gregorowski	Great Ormond Street, London. Nurse Consultant in Adolescent Medicine
Graeme Kerby	Patient Representative, Manchester

Remit

1. To audit current practice in haemophilia centres by means of a questionnaire. A draft has been circulated to the members for comments to be returned to the chairman by Tuesday 19th January.
2. To collate existing transition guidance and produce a national guideline for transition in people with haemophilia and other bleeding disorders.

Progress Report

1. A questionnaire was circulated to all haemophilia centres in 2010. The data from this audit is shown below.
2. The task force had a meeting in person April 2011 which was extremely useful. Several issues relating to transition were discussed. The outcome was a plan to produce a short document for circulation to haemophilia centre with some recommendations and suggestions, rather than a formal guideline document. This is currently under development. It was very helpful to have the views from our patient representative. Where adult and paediatric care is separate both centres need to ensure that their treatment and prophylaxis policies are concordant. We noted that there are additional issues for girls in transition.

Transition Task Force: Report on the fact-finding questionnaire:

A questionnaire was developed by the task force and sent out to all 82 UK haemophilia centres (HCs 55 and CCCs 27). The questionnaire was sent out on 18th February 2010, and a reminder was sent on 17th May 2010.

Results:

A total of 28/82 (34%) responses was received,

16/27 (59%) Comprehensive care centres, and

12/55 (22%) haemophilia centres

All the HCs were seeing both adults and children with good support from paediatricians apart from one centre where the paediatric support is minimal and this makes it difficult to provide optimal care for children. Not all questions were answered.

Twelve centres had some type of formal arrangements for transition planning, either transition clinics or workshops, 6 had informal arrangements, and 7 either had none, or found none was needed as the same team of doctors saw the young people right through the age range and considered this to be seamless transition (5 centres, 3 of which are CCCs).

Fifteen centres had no protocol for transition, 3 already had a protocol in place, and 5 centres were in the process of development. Where they have been developed it was generally by the Centre Directors and Clinical Nurse Specialists working together. One CCC had a Trust-wide policy.

One centre had some funding support for a part time person working on transition policies across the hospital. This was a CCC, one of two centres (the other a HC) which had inpatient facilities for teenagers.

Awareness of national guidance: Only 9/28 (32%) Centre Directors were aware of the DH national guidelines; 12/28 (43%) were aware of the 'You're Welcome' quality criteria.

Use of websites – 10 (36%) centres recommended some websites, but for several of these, only The Haemophilia Society (or in some cases other haemophilia-related sites) was cited rather than any websites that might explore adolescent issues more widely. 15 centres did not recommend any websites.

Age at first discussion of transition and time of transition:

The age at which discussions about transition should begin ranged from 11 to 16 years and the distribution of the ages is illustrated in Fig 1. Seven centres replied that the age at which to start discussion would be variable and dependent upon the maturity of the young person.

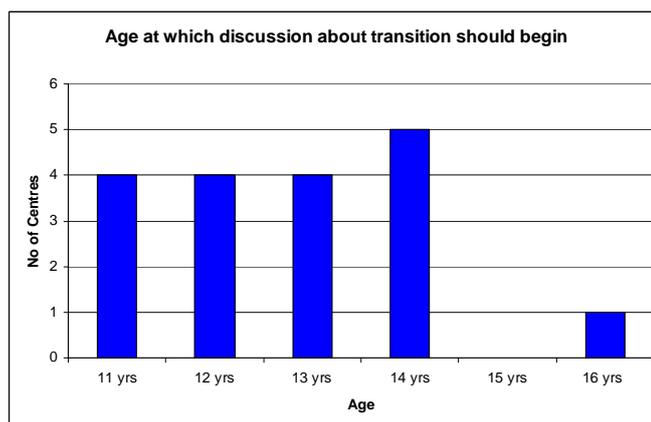


Figure 1

In contrast, the age at which a young person should be moved into the adult sector was most commonly 16 yrs.

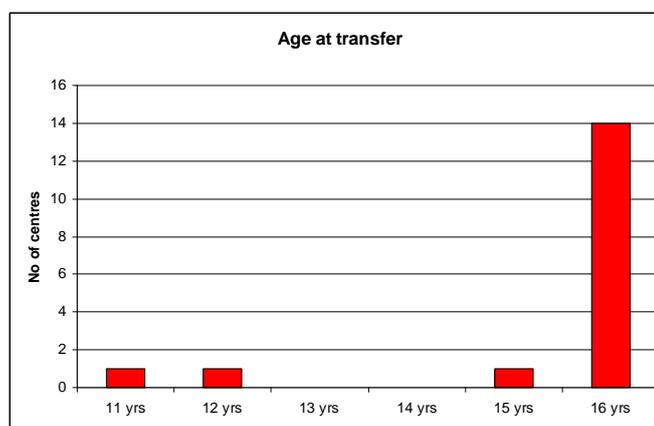


Figure 2

The age at which a young person would be encouraged to have the clinic visit on his/her own was most commonly answered as 'variable' - n=6, or not answered at all - n= 8. Where ages were quoted, they were: 12 years, 13 years one each, 14 years 3 replies and 16 years, one reply.

Most centres did not formally discuss confidentiality with the young person but 'assumed' it as part of general hospital policy. Five would specifically discuss this. This may represent a failure to appreciate the importance of a young person knowing that what they say in their clinic visit will not be discussed with a parent without their permission, which might represent a big step for both the young person and the parents.

Adolescent health issues would be addressed by Centre Directors and/or Clinical Nurse Specialists; in some centres with the help of Social Worker or Paediatricians. One centre has a 'transition team'. This is the CCC with a Trust-wide policy.

The main issues to be addressed with adolescents were usually haemophilia-related, specifically adherence to prophylaxis and fitting treatment in with an adolescent life-style. Eight centres specifically mentioned sexual health, and only 5 mentioned alcohol and drugs. Diet and weight (obesity) were raised by three.

Only 6 centre respondents had received training in adolescent issues but a further 4 had somebody with adolescence training in their department.

The final question addressed the issue of how to help the parents 'let go'. Several respondents would encourage the patient to become independent and acknowledged that there was often parental anxiety. It is important to engage the parents in the process of transition; both the young person and parents may be fearful of change so that introduction to the new team well before the event of transfer is likely to be beneficial and to allay some of the fears. One centre had found that 'transition clinics' did not work. Another centre commented that parents are not allowed to accompany the young person after the first visit in the adult sector. Another recommends a session with a psychologist. It may be difficult for the young person to be told the information about vCJD risk which the parents have kept from him/her up to this moment. Another respondent noted that arranging meetings between the young people in the process of transition and older people who have made the transfer was often helpful in allaying their anxieties.

Additional comments:

This data was discussed at the transition task force meeting in April 2011. National guidance (and other literature) recommends that discussions about transition start around 12 years of age, but the majority of respondents to this question, 10/18 centres, started later than this. We noted that there was a general lack of knowledge or appreciation of adolescent health issues. While many centres perceived themselves to have seamless transition with the same team of doctors and haemophilia nurses caring for children and adults, this may have disadvantages – the adolescent starting to explore sexuality/alcohol/drugs may not want to talk to the nurses and doctors he/she has known as a child. It would still be important to 'transition' the young person in his/her knowledge of his own disorder, to enable him/her to advocate for him/herself and encourage him/her to be seen without other family members whose presence may inhibit some of the issues which need to be discussed (e.g. menstruation in teenage girls with bleeding disorders, risks of pregnancy etc.).

New resources

In addition to national guidelines on transition published some years ago, the DH has produced an updated version of the 'You're Welcome' criteria for young people which can be found on the DH website. The Royal College of Physicians has now developed a 'Young Adult and Adolescence Steering Group' working with representatives from many specialties. An excellent e-learning programme on adolescent health is available (in partnership with the RCPCH/RCGP) and is free to all health care professionals within the NHS – see <http://e-lfh.org.uk/projects/ah/index.html>.

Dr Paula Bolton-Maggs
Chair, Transition Working Party
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