

# Making the Transition from Paediatric to Adult Services: A Parent's and Young Adult's Perspective on a Long-Term Patient's Experience

Ruth Reavley

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A diagnosis of proximal focal femoral deficiency at 20 weeks into her second pregnancy radically changed Ruth's experience of hospitals. Four Iliarov frames (one double), a couple of tendon releases, three epiphysiodeses and lots of physiotherapy later (not to mention numerous childhood breaks of other bones owing to stumbles and falls), David is 17, about to start A2 courses, has been on crutches now for 4 years owing to knee subluxation, and is hoping that a knee replacement after exams next summer will regain his independence in walking. Ruth is a member of the BOA Patient Liaison Group

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Teenage patients move from paediatric to adult orthopaedic services around the age of 16. Some have built up life-long experience and networks with clinical teams and physiotherapists in a paediatric service setting. The transition typically severs those personal relationships. Managing the transition from these familiar settings to new and unfamiliar adult settings involves careful planning by healthcare professionals, and adaptation by the patient and the parent/carer. The tone and pace of consultations are different. The support role of the parent changes.

The biggest surprise came in the impact that a change of clinical team and setting had on our son's capacity to deal with new situations emotionally. Rationally he was ready to move. A great deal of care had been put into planning the best point in treatment to make the change. But the simultaneous experiences of unfamiliar adult settings, a clinical team he was just getting to know, some pretty big decisions to be faced, and the first experience of signing the consent form (rather than countersigning a form I had signed), had huge impact on his emotional capacity to cope. Reflecting, several months on, we realised that for some months immediately following the transition, he felt more vulnerable than either of us had appreciated.

For many years, my roles in relation to our son's treatment have centred on understanding the condition and proposed treatment (sharing the task of explaining in age-appropriate ways when he was very young), and motivating him on physiotherapy. The transition to our son taking primary responsibility for understanding his condition and treatment was made over a number of years. Encouragement to do the physiotherapy is a perennial parental responsibility.

Acknowledging that one family's reflections merely make a unique case, I nonetheless invite readers to consider the wider and deeper picture. Virtually everything is changing for the young adult long-term patient except their underlying condition. As a result of these experiences, I led the development of a document on 'Managing the transition from paediatric to adult services' by the BOA's Patient Liaison Group, of which I am a member. The document has recently been published online and is reproduced in full for JTO readers on page 32.

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# Features

## Making the transition

By the time a long-term orthopaedic patient reaches sixteen, they have probably had enough of the dressing up corner, the Lego, play kitchen and children's comics, which are staple offerings in the waiting room. However the absence of graduated 'in-flight' waiting room entertainment is, in our experience, more than ably offset by the steady adaptation in the manner of treatment by staff in the paediatric unit.

Everyone at the clinic should be aware that adolescent patients who may be relatively tall and, if male, deep voiced, can be quite intimidating to the smaller patients.

### The 'good practices' we experienced in the run-up to transferring to an Adult Unit were:

1. Age and development-appropriate involvement of the patient in discussion about treatment and risk factors
2. Encouragement to countersign surgery consent forms as a patient approaches 16 years old
3. Information about the name and specialism of the adult services consultant who is to pick up care
4. Age-stratification of bays in wards
5. The offer of high-tech distractions such as GameBoys (to complement any 'must-have' items brought in e.g. the iPhone/iPod, which incur extra insurance cover for parents)
6. Age and development-appropriate vocabulary used in explanations

## What is it like for a parent to shift from being essential to being an optional extra in consultations?

Until a child is 16 they have to be accompanied by an adult who will give consent to treatment. As a parent I had to be at every clinic. Suddenly – overnight – I am considered an optional extra.

However, as my 17-year-old says: it's crazy not to have me in clinic appointments as I'm the one who does the caring, the transportation, the reminding about routines, the negotiation with school about time off the premises, and he relies on me to share an understanding and perspective on proposed treatment. So it's essential that there is a gradual transference of responsibility and autonomy to allow the pending adult to acclimatise to the extra responsibility!

I have found it good practice to always ask our son before clinics whether he wants me to be in the session with his consultant. I always say on arrival that our son has asked me to be present. And I've taken to asking when it's clear the consultation is rounding off, whether our son has anything he wants to raise without me being there. I'd leave if he wanted me to.

## Passing responsibilities over to the patient

We'd agreed, from about age 15, that our son would announce himself to the reception desk in clinics and had responsibility for taking the clinic letter.

From about age 12, we discussed the advice given in clinics and wrote down a shared understanding in a book which the whole family could look at. (Previous to that, I'd kept a record, but not one based on explicitly shared understanding.)

I gradually withdrew myself from physiotherapy appointments from about age 14 (puberty alters the mother-child dynamic, and this seemed like a good way to demonstrate that I was truly offering independence). I was present, but disengaged from the conversation (reading, in the same room). If my involvement was sought (by son or physiotherapist), then I was there and immediately available. I don't go into physiotherapy appointments in the adults' services provision, but, as transport provider, am on hand should I be wanted.

## What does a smooth transition to adult services look like?

1. Appointments coming through promptly – with continuity and good communication between the two clinics
2. Some level of negotiation on physiotherapy to adapt to free periods and school hours (rather important alongside A2s and AS level public exams)
3. A willingness from all parties to respect the non-obligatory role of a parent in clinic discussions

## What has surprised us so far?

Visiting hours are different in adult wards – typically being much more limited. Whereas it had been routine for me to attend ward rounds in the Children's Hospital it's not necessarily possible to turn up to early ward rounds at an Adult Unit. This represents a real change in support for the patient.

On the morning of the first new surgical procedure as an adult the ward round took place before I got to the hospital. Having signed the consent form at pre-op clinic when I was present, the experience of checking it and re-hearing the risks list whilst on his own, on the ward, just before surgery, caused unanticipated high levels of anxiety. It seemed that all the times they'd been recited before (a surgery list going well into double figures), our son had 'zoned out' as it was something I was signing for. The risks on this occasion were no different. His being the sole participant in considering them was new – and personally challenging. Young adults may need additional help to manage this step in independence. The clinicians involved in the conversation may not have thought about the impact of their words on a young adult taking sole responsibility for signing consent for the first time, and may not 'read' the patient's anxiety proficiently.

Department of Health Policy guidelines are summarised in *You're Welcome* (March 2007). The introduction states: All young people are entitled to receive appropriate health care wherever they access it. The *You're Welcome* quality criteria lay out principles that will help health services – both in the community and in hospitals – to 'get it right' and become young people friendly. <http://www.nationalarchives.gov.uk/20130401151715/https://www.education.gov.uk/publications/eOrderingDownload/275246.pdf>

More recently the Department of Health has published Quality criteria for young people-friendly health services (April 2011) as an extension of this initiative. This paper reflects on paragraph 8.3. [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/152088/dh\\_127632.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/152088/dh_127632.pdf)

### Summary:

- Adolescents need managing differently from pre-teenagers.
- Waiting rooms and wards need to reflect the needs of post-pubescent patients.
- Health care professionals should ensure they treat post-pubescent patients appropriately.
- Patients and Parents need to adapt the way they discuss and manage hospital visits as the patient approaches the transition to Adult Services. This may be problematic where the parent has no personal experience of adult units.
- Children's Hospitals need to ensure they prepare patients for the transfer to an Adult Unit.
- The Adult Unit (Clinic or Ward) needs to ensure the patient and their family are aware of, and comfortable with, the different practices.

The Adult Unit needs to understand that young adults may feel vulnerable when they first attend an adult clinic or have their first adult ward admission.

The 'Managing the transition from paediatric to adult services' document by the BOA's Patient Liaison Group was published in Summer 2013 and is available online at [www.boa.ac.uk/PI/Pages/plg.aspx](http://www.boa.ac.uk/PI/Pages/plg.aspx)