



## Further Reading...

### Web-based Resources:

Surviving Adolescence:

Leaflet for parents of teenagers [www.rcpsych.ac.uk](http://www.rcpsych.ac.uk)

### Looking After Ourselves:

Leaflet for parents re looking after their own mental health [www.youngminds.org.uk](http://www.youngminds.org.uk)

Free online family advice

[www.relateforparents.org.uk](http://www.relateforparents.org.uk)

### Contact a Family:

The only UK-wide charity providing advice, information and support to the parents of all disabled children - no matter what their disability or health condition.

[www.cafamily.org.uk](http://www.cafamily.org.uk)

### Publications:

The Young Mind—Co-edited by Sue Bailey and Mike Shooter (User friendly handbook for parents, teachers, professionals)

Consent - what you have a right to expect: a guide for parents (Department of Health 2001)  
Available at [www.gov.uk/dh](http://www.gov.uk/dh)

Advice about Parent responsibility Available at [www.bma.org.uk/ethics/](http://www.bma.org.uk/ethics/)

chat 2 parents – arthritis in teenagers Booklet produced by the CCAA, LadyHoare Trust and Arthritis Care.

Available from the Rheumatology Team

## Department of Adolescent Rheumatology

Occupational therapist

0121 333 8212

Physiotherapist

0121 333 8221

Nurse

0121 333 8219

Consultant

0121 333 8209

## Data Protection

We collect information about our young people and families relevant to their diagnosis and treatment.

We store it in written records and on computer. We may have to share some of your information with other people and organisations. If you have any questions and/or do not want us to share that information with others, please talk to the Adolescent Rheumatology team or contact



## Transition FAQs for Parents & carers

Adolescent Rheumatology Advice...  
**guide**  
for parents  
and carers

 Like us on facebook:  
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[@RheumatBCH](https://twitter.com/RheumatBCH)

E: [questions@kidslikeus.info](mailto:questions@kidslikeus.info)  
[www.kidslikeus.info](http://www.kidslikeus.info)



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### What does Transition actually mean?

Transition is a process which ensures that not only the medical needs of young people are addressed as they move from child centred to adult centred services, but also the psychological, social and educational/vocational needs.

### When should Transition actually start?

Transition is a process, ideally starts around the age of 11, as young people prepare to move from primary to secondary school. Children don't stay at primary school for ever and so they won't stay at a children's hospital forever!

### Why bother?

Research has shown that when young people and their carers first make the move or transfer from paediatric to adult healthcare services, they feel nervous about the change. When they are well prepared for this move however, they find it easier to cope in the new situation. The skills gained during the transition process can also be useful in other aspects of life e.g. the clinic environment is a safe place for young people to start practicing skills (and gaining confidence!) such as talking to professionals on their own.

### Who is involved in Transition?

Everyone! This includes the young person, you - their family, the rheumatology team, their school, community services and even voluntary agencies.

### What if I find it difficult to "let go"?

This is perfectly understandable. It's all part of being a parent of a teenager! Just as parents watch their children develop in early childhood - the first smile, the first step - there are also important milestones in adolescent development. Many parents find that learning about these normal adolescent milestones and in particular how chronic conditions affects these milestones, helps them support their young person during this exciting - sometimes challenging time - of their lives (and yours!). Some useful resources can be found at the end of this leaflet. And...never be afraid to talk things over with the Rheumatology Team.

### Will I be told everything that is said to my son/daughter if they choose to be seen alone?

As young people mature and develop they can choose to be seen independently. They have a right to confidentiality, whatever their age, unless they or someone else is at risk of serious harm. In practice, with the agreement of a young person, health professionals will usually discuss relevant information with parent(s), whilst respecting the young person's right to confidentiality. See the Department of Health website ([www.gov.uk/dh](http://www.gov.uk/dh)) for more information. Some parents worry that their son/daughter won't remember what to tell or ask when they are seen alone. One solution is to sit down with them the night before the appointment and write a list of questions to be discussed. The doctors will then know your concerns as well as those of the young person



### When will transfer actually happen?

The current hospital policy is that young people should transfer to adult care between the ages of 16 to 18 years. Timing of transfer will depend on several factors, for example:

- Maturity
- Medical status – it is best to transfer a young person when they are going through a good phase, that is, in remission.
- Their ability to manage their condition largely independent of parents and staff
- Whether they feel confident to see the rheumatology team on their own

### What do I need to consider as a parent during transition?

It is important that you know about your son or daughter's condition and its management, and what is likely to happen in the future (their prognosis). It is also helpful for you to be aware of resources available on a wide range of health issues important for all young people in today's world such as mental health (including bullying), substance use, sexual health, careers, etc. Finally, it is important to be aware of the differences between paediatric and adult rheumatology services, and which adult rheumatology service your son/daughter will be transferred to.

At any given time 1 in 1000 children will also suffer from Arthritis

1 in 3 people in Birmingham suffer from Arthritis or inflammatory conditions.

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