



# Making the leap

**A**s you get a bit older you might decide that you want to start visiting your doctor without your parents to discuss your medications and overall health. However, taking responsibility for your own healthcare can take some getting used to – it means remembering to attend your appointments and having the confidence to discuss your health with your doctor.

For some, going straight from a child clinic, where your parents may have done most of the talking to healthcare professionals (possibly leaving you wondering why nobody is talking to you), to the adult clinic might seem too big a leap.

Adolescent clinics aim to bridge this gap and make the change, or transition, easier. However, a survey in 2000 revealed that only 9 of 61 arthritis units have any type of service dedicated to teens. Dr Janet McDonagh, who runs an adolescent rheumatology clinic in Birmingham, is campaigning for more specialist services for teenagers with arthritis in the UK.

## Game plan

According to Dr McDonagh, the move from child to adult clinics should be a gradual process. This should ideally start at age 11-12 years when you are usually moving from primary to secondary school and therefore

Moving from the security of the child rheumatology clinic to the unknown world of adult services is a major leap. **Emily Ross** finds out why specialist services for adolescents are needed...

realising that change is a part of life. Adolescent clinics are designed to teach you the skills which can make you feel confident enough to come to appointments alone and to ask the right questions about how to access services and manage your condition.

Dr McDonagh believes that all young people with arthritis should have an individualised transition plan which they and their healthcare team will develop and work to. What's this? Well, it's a written plan, including details of your future medical care as well as any issues you wish to discuss, such

as body image, sexual health and education/career plans.

## All talk, talk, talk

As well as preparing you for the world of adult clinics, adolescent clinics are a place where you can talk to health professionals about anything that is worrying you.

Toni Neufville (22) certainly felt that she was put at ease when she met the manager of the adolescent clinic she attended. 'I was very apprehensive and worried about the idea of changing hospitals. However it was made easier because I got really clear answers from the doctors

and I was able to address all my worries. Mostly I was after reassurance – was I going to be OK, and silly things like what colour the walls would be,’ says Toni.

Toni feels that she really benefited from being in an adolescent clinic. ‘Once I was at the adolescent clinic I really liked it – I made friends with the other people there and the nurses were really nice too,’ says Toni. The staff in the adolescent clinic helped Toni get used to the idea of moving to the adult clinic by telling her about it two years in advance. Toni also appreciated the support from the clinic in mapping out her career choices.

### *Hitting the wall*

According to Dr McDonagh, young people with arthritis should be able to make a successful transition to adult care by their late teens. However, she says that this is not always the case as some young people still lack confidence at this age.

Toni certainly had problems adjusting to the adult clinic. ‘The first visit was the most daunting experience ever. Seeing all the old people there – I just didn’t want to be there,’ she says.

Toni, like many other young people, remains unsettled in the adult clinic and sometimes doesn’t get in touch with the clinic even when she is unwell. She often feels isolated and says: ‘Before I moved I could talk about anything I was worried about. It isn’t like the adolescent ward where people know you and your history – sometimes I really feel like I’m on my own.’

Katrina Farmer (21) from Peterborough has also had problems with adult care – she was shunted about from clinic to clinic and felt that she did not get the support she needed. Katrina did not receive any transitional care as a teenager.

The adult clinic organised separate sessions for her with the rheumatologist and with her surgeon, which was upsetting and frustrating for Katrina and her family because they told her different things. ‘When you are going back and forth from doctor to surgeon you spend all your time explaining your history, and this stops you from moving forward,’ says Katrina.

### *The way forward*

The Government has said that it wants to see young people supported in their healthcare to make the transition to adulthood. In England, the Department of Health has published a guide to transitions,



**Fitting in – specialist services for adolescents with arthritis**

which states that transitional care should be provided in a co-ordinated and uninterrupted way, in an appropriate environment and in consultation with young people.

Dr McDonagh is optimistic that the recent campaigning for transitional care will lead to change. She says that making professionals aware of the problems should hopefully encourage them to start doing things differently. ‘Training will help staff to communicate with teens, understand what they are going through and enable them to learn more about their disease,’ she says. ‘Most doctors and health professionals

aren’t trained to deal with teenagers and this needs to be addressed.’

Toni recognises that transition is a part of life. ‘When you have to move clinics, all you want is to feel ready and supported and sure that you will be comfortable and happy with your new clinic before they sign you off. We need people to remove their hands from their ears and start listening to what we are saying.’ ■

**Tell us about your experiences, write to The Editor, No Limits, 18 Stephenson Way, London NW1 2HD, email: [NoLimits@arthritiscare.org.uk](mailto:NoLimits@arthritiscare.org.uk)**

## **What can I do if I’m not happy with the support I’m getting?**

- ➡ **What’s the score?** Log onto the Department of Health website ([www.dh.gov.uk/transition](http://www.dh.gov.uk/transition)) and download *Transition: getting it right for young people* to find out what you can expect from transitions in England. You can also order the free DVD made by young people to educate health professionals about transition.
- ➡ **‘Ave a word’** Talk to your healthcare team about what you want. Wherever you are in the UK, get them to watch the DVD (see above). Ask them if there are any services for adolescents in your area. Let them know what would help you make the transition.
- ➡ **The world at your feet** Chat to other teens about transition at [www.dreamteam-uk.org](http://www.dreamteam-uk.org) – or (if you are 15 or over) have your natter in the Young People Zone on the Arthritis Care website: [www.arthritiscare.org.uk](http://www.arthritiscare.org.uk)