

Young ambassadors project

Improving transition and young adult
care in Rheumatology



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TRANSITION

- Age and development appropriate process addressing psychosocial, educational and vocational aspects of care in addition to medical care
- Goals : optimize health outcomes and facilitate young person to be resilient, independent and achieve their potential in life
- Adult services and transition:
 - Involved in *transfer*, not in *transition*
 - Very little preparation in adult services to receive transitioned patients
 - Often patients are offered “routine” management and care
 - Challenges: morbidity, compliance with drugs, lifestyle changes, anxiety (patient/family), continuation of care

Liverpool Transition model

- 3 monthly transition clinics in Alder Hey Children's Hospital
- Transition nurse
- Four Young Adult Clinics/year at Aintree site for 16-25y olds
- Transition and adolescent onset diseases
- Coinciding with university/college holidays
- Longer slots than adult clinics
- Holistic approach
- "Do not attend" flexible policy



- Brilliant...we have such a great setting!



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But...have we asked the young people?

Informal chats and focus group:

ENVIROMENT

- *Sometimes it's not very nice being the only young person in the waiting room.*
- *I can see the other patients looking at me and wondering why I'm here.*
- *I rarely see any other young people when I come to clinic*
- *When I see some of the more disabled patients I wonder if that's how I'll end up.*
- *I get that it's not all about me, but it would be nice to have an environment and literature that's more appropriate for younger people*

WHAT I WOULD SAY TO YOUNGER SELF

- *Calm down, it will be fine*
- *Initially it's daunting, but it's not traumatic*
- *The team from Aintree adult services came to Alder Hey to meet me before I moved over*
- *Was really close to Alder Hey team but really surprised by how quickly I formed a good relationship with the Aintree team*
- *The CNS and clinical team are really supportive*

Working with our young ambassadors:

1. Enviroment:

- **Posters** showing real patients attending our clinic to be displayed in the waiting area, with inspirational, realistic and personal messages
- Review displayed literature

2. Sharing :

- **Short videos** focusing on our young patients experiences to be on offer to younger patients before transition.

3. Support:

- Self managed group/patients focus group



“I couldn’t go to the park with my daughter if it was not for my treatment. It feels good to be an adult.”

Young Ambassador Project
Declan, 25
JIA



“I feel prepared to manage my condition in a way that fits with my life.”

Young Ambassador Project
Sophie, 20
Juvenile SLE



“Ask your own questions, be confident. You are the only person that knows what you are going through.”

Young Ambassador Project
Jemima, 20
JIA

- Sop



- Next steps:
 - Sharing good practice within department and organisation
 - Encouraging young people to meet and feedback
 - Measuring satisfaction

With thanks to:
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Patients/Young Ambassadors