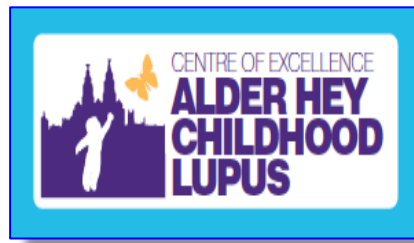




Alder Hey Children's **NHS**
NHS Foundation Trust



UNIVERSITY OF
LIVERPOOL

Lupus and You

Workshop for young people with
lupus and their families

Summary Report

Alder Hey Children's NHS Foundation Trust
24th September 2016

Report by Dr Emily Wilson of behalf of The Lupus Team,
Centre of Excellence for Childhood Lupus at
Alder Hey Children's Hospital

Background

Why a workshop?

Following the success of the first *Lupus and You* event held in March 2016 at the UK's only paediatric Lupus Centre of Excellence at Alder Hey Children's Hospital, a second workshop was developed. This was again a day-long workshop, to be attended by young people with lupus and their families. The event was developed and run by representatives from the lupus multidisciplinary team as well as colleagues from the hospital research facility involved in studying lupus.

Focus on Medicines and Transition

Feedback from the initial workshop identified medicines and treatments for Juvenile Onset Systemic Lupus Erythematosus (JSLE) or *lupus* as being topics that families and patients wanted to know more about. Given the age of the current cohort of patients, transition was also identified as an area requiring timely consideration.

Attendees

The workshop was attended by:

- 6 families including
 - 5 young people with lupus
 - 1 sibling and
 - 7 parents
- 9 staff members from Alder Hey Children's Hospital representing both the lupus multidisciplinary team and research facility
- Dr Cristina Estrach (Consultant Rheumatologist) and Ms Lorraine Brinkley (Nurse Specialist) from Aintree Hospital's Adult Rheumatology Service.
- Mr Kevin Weston (Chair of Lupus UK) and Elaine Holland (Acting Chair of NW Branch of Lupus UK)



Introductions and Icebreaker

At the beginning of the day, staff and attendees were encouraged to take part in an ice-breaker exercise in order to share factual or humorous information/knowledge about themselves; thus helping to relax the group and set the tone of discussion and collaboration for the day ahead.

Medicines Workshop

Attendees listened to a presentation on medications and medical treatments used in the management of JSLE presented by Jane Kelly (Nurse Specialist), Dr Eve Smith (ST6) and by guest speaker, international lupus expert, Consultant Paediatric Rheumatologist, Professor Michael Beresford. Questions were anonymously submitted to the speakers who then discussed their answers with the group (for further details or a full copy of this report please contact Lupus@alderhey.nhs.uk).

Key themes included:

- Need for life-long medication
- Medication side-effects
- Accessing medication in adult services
- Lupus symptoms
- Patient participation in research trials
- Treatments for lupus



Transition

Questionnaire

At the start of this section, young people and their families were asked to complete a bespoke questionnaire enquiring as to their knowledge and concerns regarding the process of transitioning from paediatric to adult services.

Group

The attendees were then divided into two groups (parents/family members and young people). One group met with staff from Aintree Hospital's adult rheumatology service (Dr Christina Estrach, Consultant Rheumatologist and Lorraine Brinkley, Nurse Specialist) which receives a number of patients from Alder Hey Children's Hospital. The other group met with two young people who had transitioned from Alder Hey lupus service to adult services within the last couple of years. The aim of these discussions was to enable the parents and young people to feel able to openly discuss any concerns they might have and raise questions with those with experience of the relevant issues.

The main themes highlighted by both young people and their parents covered the practicalities around transitioning, as well as issues associated with the young people gaining increasing independence and responsibility for managing their health.

Attendees highlighted what might be good about transitioning, for example the young person having greater control and easier access to medications, as well as the issues they felt worried about, for example new doctors, stress and being able to express themselves within adult services. Suggestions were made by young people and their families regarding what support they might like from the paediatric and adult services to help them in understanding and following through with the process of transitioning, such as being given advice about how, when, and where to transition.

RAIiSE (Raising Awareness of Invisible illnesses in Schools and Education)

Sophie Ainsworth, a current service user, spoke to the group about a project she has developed called RAIiSE (Raising Awareness of Invisible illnesses in Schools and Education). She explained how the idea for the project came from her own personal experience of struggling to access the support she needed to manage her health needs within school. She is now working together with relevant stakeholders (parents, families, teachers etc.) to develop resources to support young people in managing their 'invisible illnesses' within school/college/university. The group were very enthusiastic to hear about the project.

Workshop Evaluation

All young people and their family members were asked to complete an evaluation form at the end of the event. Attendees found the workshop to be 'helpful'. Young people were most complimentary about the medication session, meeting other service users and also meeting clinicians from the adult service. The family members similarly were most favourable about the medication session, meeting other families as well as receiving transition information and discussions with patients who had been through the transition process.

The young people who attended, and the vast majority of family members present, said they would be interested in coming to future workshops.

All young people and families present were asked to identify topics they felt would be useful to cover in future sessions. These included topics such as how to explain lupus to friends and family and future medication processes (once transitioned) as suggested by the young people, and how to recognise symptoms, how to combat symptoms and flare-ups and pastoral care and exam support at school/college as suggested by the family members.

Next Steps

The day concluded with a summary of the day's discussions and consideration of next steps. Attendees commented on having had an enjoyable day.

All attendees have been contacted by letter to thank them for attending and to encourage them to be in contact should they have any questions or queries from the day that they might like to follow up on with a member of the team.

Discussions are now being held within the lupus multidisciplinary team to consider possible topics and dates for a future workshop.

This short summary of the day will also be shared with Lupus UK and a blog will be posted on the GenerationR website: www.generationr.org.uk

For further details or a full copy of this report please contact:

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