

Autoimmune Liver Disease Day February 2019: Summary

1.0 Background

Approximately 25 children are diagnosed with Autoimmune Liver Disease (AILD) at King's each year, mostly within adolescence. The diagnosis and its treatment can negatively impact on a young person's school attendance and achievement, body image, peer relationships, quality of life and emotional wellbeing. High rates of non-adherence are seen amongst adolescents with chronic illness, with the service recognising that young people diagnosed with AILD in adolescence seem to be at particularly high risk. Non-adherence to treatment can result in poorer health outcomes and avoidable liver transplant. The liver transition service adopts an assertive approach to engage young people in their care and promote adherence from point of diagnosis. Peer support has been shown to be an effective component of engaging young adults in services, improving health outcomes and wellbeing. A need was therefore identified to develop a group to promote peer support within this population.

2.0 Overview

2.1 Aims

The day aimed to:

1. Increase opportunities for young people and parent's/carer's to connect, share and hear experiences, and reduce feelings of isolation
2. Promote positive adjustment to illness and treatment for both young people and parents/carers

2.2 Format:

The event ran through the morning (09:30 – 12:30), with young people and Parents/ carers separated into parallel streams. Attendees were given two tickets to watch the West End theatre show 'Wicked' following the morning session (14:30- 17:15 pm) (Paid for by Redthread a youth provision charity).

The day was facilitated by:

1. Multidisciplinary team from the transition liver service
(Youth Worker, Clinical Psychologist, Family Support Worker, Clinical Nurse Specialists, Paediatric Social Worker)
2. 'Young Mentor' – Two young adult patients aged 22 and 25 who were diagnosed with Autoimmune Liver Disease during their teenage years.

The aims were achieved through:

1. Information provision:
 - a. Team introductions and the promotion of available support from the MDT.
 - b. Question and answer session with the young mentor
2. Peer support:
 - a. Small group tasks & discussions between young people
 - b. Small group tasks & discussions between parents
 - c. Opportunities for young people to socialise (e.g. afternoon trip to see Wicked)

3.0 Participants

Invitation letters were sent to all patients who were:

1. Aged 12-16 years' old
2. Had been diagnosed with AILD within the past two years

Letters included information about the group, including a group activity after the information sharing part of the day. The theatre performance was not specified until after attendance was confirmed

- Twenty-eight patients were invited to attend the event.
- Response rate of 31%, with 9 patients accepting the invitation.
- On the day six patients attended the group, each with a parent or carer.
- Participants were all female, aged between 13 and 15 years.

4.0 Feedback

All young people, parents and mentors were asked to complete a questionnaire about the day. A follow up email was also sent to the parents or carers following their attendance of 'Wicked'. Please see the attached summary for the collated results.

5.0 Limitations

The feedback suggests that for those who attended, the AILD Day was a valuable experience. However, there are several limitations to consider:

1. Female only responders:
 - a. Due to a female preponderance in the development of AILD we would expect a higher response rate from girls; however, it was noteworthy that no boys expressed any interest.
 - b. This was also the case for the last AILD day that was run and therefore we need to explore how we can make
2. Response rate:
 - a. It must also be noted that although the invitation was sent out to twenty-eight patients only 6 patients attended.
 - b. Feedback from those who did not attend was mainly centred around not wanting to miss school which raises that idea of whether holding future events on a weekend or during school holidays will help to increase the number of participants attending.
3. Age of Young People
 - a. Even though the event was promoted to patients aged 12-16 there was a cluster of patients aged 13-14 were in attendance.
 - b. Feedback from one of the older patient said she would have loved more young people her age (14+)
4. Unforeseen circumstances
 - a. On the day of event there was a problem with the train lines which meant that many patients arrived late.
 - b. This could also be related to the time of the event and potentially starting event later in the day could allow for more time for those patients travelling from far.

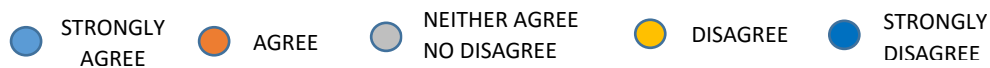
Please see patient feedback on the following pages.

For further information please contact Ajua Mensah (Liver Transition Youth Worker) on ajua.mensah@nhs.net.

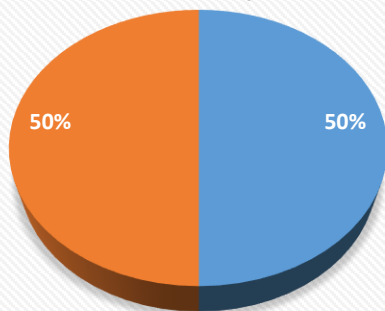
Autoimmune Liver Disease Day

Young people's responses:

Question	Rating scale	Mean rating (n= 6)
How enjoyable did you find today?	0 (not at all) – 10 (very)	8
How helpful did you find today?	0 (not at all) – 10 (very)	9
How useful did you find it to meet other young people who have AILD?	0 (not at all) – 10 (very)	9

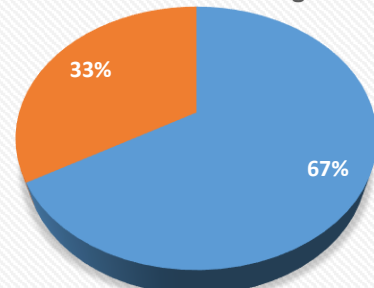


The AILD Day answered some thoughts or questions I had about my liver condition



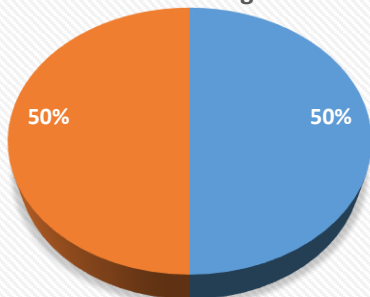
100% agree or strongly agree

Having this information makes me feel that I can deal better with having AILD



100% agree or strongly agree

The AILD answered some thoughts or questions I had about some of the challenges I may face as a result of having AILD



100% agree or strongly agree

"Reassuring that older people are fine"

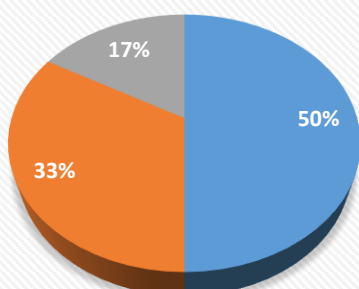
"I liked hearing how other people deal with it"

"Because I am finding out how different people deal with it"

"I feel that I can be able to speak openly about my condition with my friends and not worry about their reaction as at the end of the day it doesn't really affect me or who I am as a person"

"It hasn't helped me a lot as I don't feel lonely with this condition but the advice that more experienced people have makes me know more about the condition"

After the AILD Day I feel more positive about having AILD



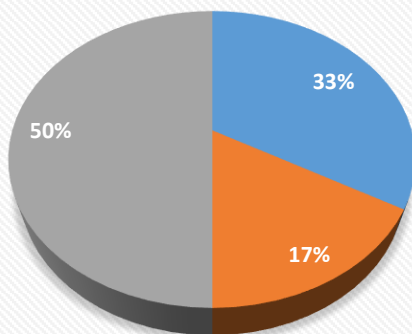
"Same feeling as before, fine with it"

"Because other people shared their way of dealing with it"

"AILD isn't really a life threatening disease and is nothing to be ashamed of as you are still able to live"

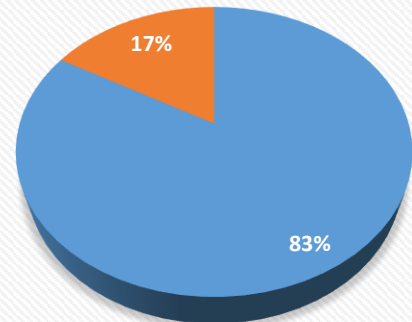
"As I very shy and scared and negative about having it and now that other people share their story I feel more knowledgeable about my condition"

After coming to the AILD Day I feel more comfortable talking to other young people about my liver condition



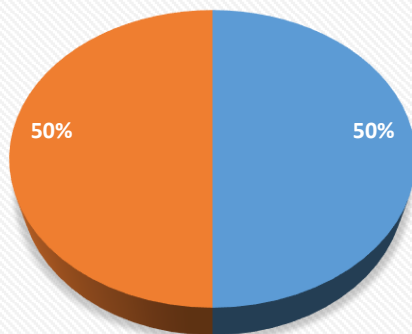
83% agree or strongly agree

After coming to the AILD Day I feel more comfortable talking to my doctor about my liver condition



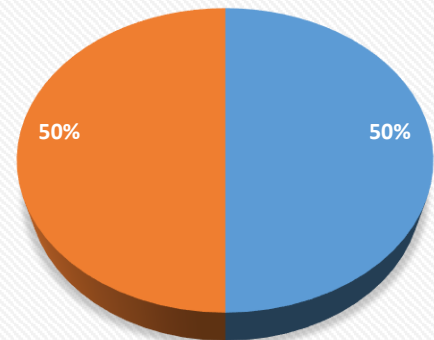
100% agree or strongly agree

After coming to the AILD Day I feel OK about taking my medication and/or going to appointments



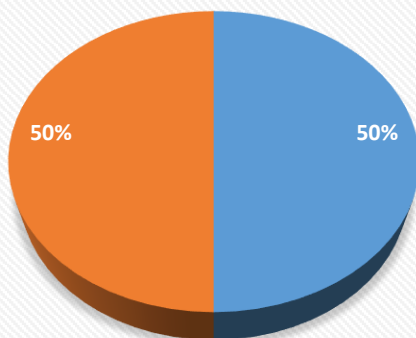
100% agree or strongly agree

What we have talked about today makes me feel more optimistic (hopeful) about my future



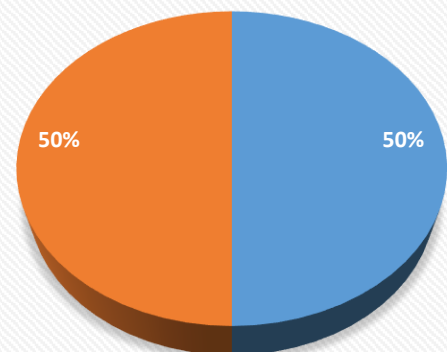
100% agree or strongly agree

After today, I think "I would like to come to an AILD Day or something similar again".



100% agree or strongly agree

Meeting the Young Mentors and talking to them about having AILD was helpful for me



100% agree or strongly agree

"I feel positive because I'm not the only one"

"Informative and cool to find out/share their experiences"

"Because we can get advice about it"

"I heard about their experiences/ challenges and I can now Take away things from that, that can help me in life"

Was it helpful for the day to only be about AILD?

- Yes, it is more direct because otherwise might be vague and it's nice that everyone can relate. Also helpful because its focussed on one condition so all relevant
- We can see how other people deal with it
- Yes, because I get to know people going through the same things as me
- I think it was helpful for the day to be only about AILD because you are able to hear/learn about things that are specific to AILD
- I find it very helpful because we get to focus more on our condition and get to learn more about it.

If we run another AILD Day, what topics or activities would you like us to include

- Maybe more about the effects of Alcohol
- Maybe more activities like the egg stuff
- I would like to talk about how you deal with exam stress or when you feel down and how to deal with it
- To get much older people that have it and to learn about their experiences and to go the theatre again or the cinema



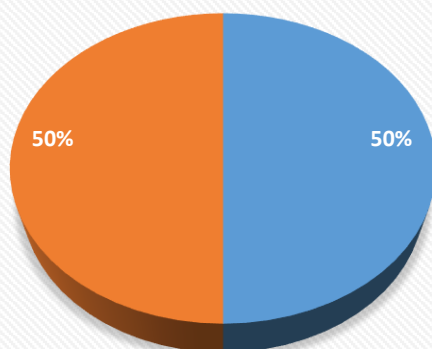
“Everything was perfect!”

Autoimmune Liver Disease Day: “Whatever the outcome, she can live with the disease”

Parents responses:

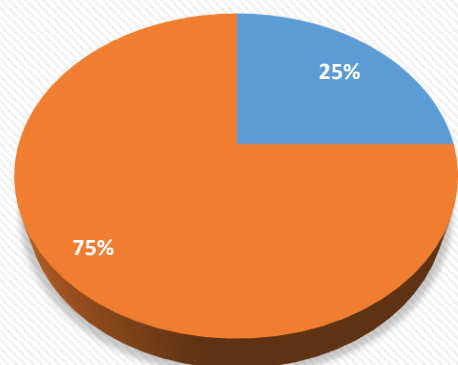
Question	Rating scale	Mean rating (n= 6)
How enjoyable did you find today?	0 (not at all) – 10 (very)	9
How helpful did you find today?	0 (not at all) – 10 (very)	10
How useful did you find it to meet other parents/carers of young people who have AILD?	0 (not at all) – 10 (very)	10
How useful did you find it to meet other young people who have AILD?	0 (not at all) – 10 (very)	10

The AILD Day answered some thoughts or questions I had about challenges my child may face related to their liver condition



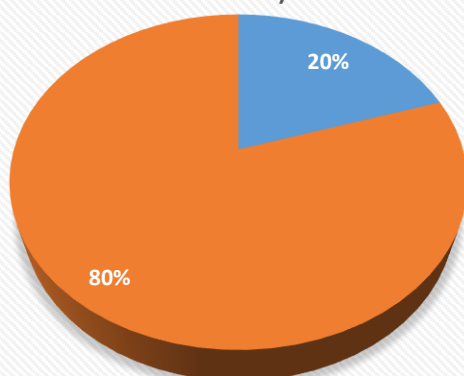
100% agree or strongly agree

After the AILD Day I feel more positive about my child having AILD



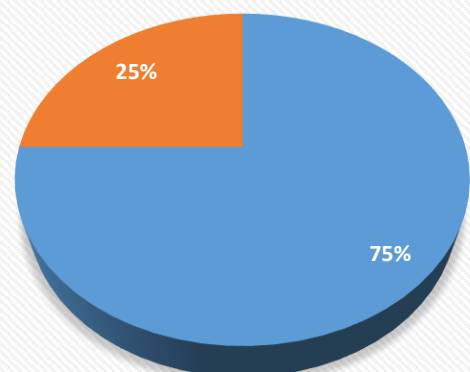
100% agree or strongly agree

What we have talked about today makes me feel more optimistic (hopeful) about my child's future)



100% agree or strongly agree

It was helpful for me to meet and speak to the young mentors who have AILD



100% agree or strongly agree

This is the first time we have run an event for a specific liver condition. Was it helpful for the day to only be about AILD?

"Yes, very helpful"

"Absolutely helpful"

What have you found most useful about today?

"Hearing other parents going through the same as you"

"That she is not the only one with the condition"

"Talking about the condition and the problems it brings"

Thoroughly enjoyed this event today would love to come another event"

"I would love to come to another event"

"I feel very helpful for myself"

"It was excellent – the opportunity to meet parents and the team taking care of our daughter was invaluable "

***"In every way Positive
Honest
Kind"***

"The location was fantastic and the team all being there was frankly superb. We feel extremely fortunate, and listening to others who are more challenged and the mentors who have overcome so much was truly inspirational and my daughter has changed her outlook since the day so please do it again."