

Patient information

Transitioning – Alder Hey to Liverpool University Hospitals

Rheumatology Department

This leaflet explains more about the transition to the adult service for young people with Lupus. If you have any further questions, please speak to a doctor or nurse caring for you.

What is Transition?

Transition is a term used to describe the gradual process of planning, preparing and moving from paediatric care to adult care.

The transition team are lupus specialist nurses involved in planning your care. Our aim is to:

- help you understand your condition better
- to prepare and support you for the changeover from paediatric to adult care
- become more independent with managing your lupus.

As you have lupus, you will require on-going treatment and regular assessment and review. The lupus nurses will discuss a number of issues with you as it is important that you understand and prepare for the changes you will go through as you grow and what this means to your care.

Who is involved in this process?

The lupus teams at Alder Hey and Liverpool University Hospitals (LUHFT) have very close links to each other, and we will all help you and your family to work out your healthcare management goals and what you need in order to reach these goals when moving from children to adult services

What exactly will happen to me?

All families are different, and what exactly will happen will depend on how much you as a young person are involved in taking care of your health. We want to make sure that when it is time to move on to the adult hospital, you have developed the right level of understanding and skills for adulthood. We also want to make sure that both you and your family feel confident about making the transition to adult services.

Having lupus means you have on-going healthcare needs. We will also be supporting you with strategies to balance your illness with other areas of your life, such as studying, socialising, sports and hospital appointments.

The Transition Clinic

Prior to transition, you will be invited to attend the lupus nurse led transition clinic which takes place in Alder Hey Children's Hospital, this is led by the Alder Hey lupus nurse Olivia.

You and your family will have opportunity to meet the lupus nurse Christine from the adult service (LUHFT- Broadgreen Hospital) who will be involved in your future care.

This clinic gives us the opportunity to discuss and plan how and when you are going to transfer over to the adult lupus team. There will be input from both the paediatric and adult lupus consultants to make sure this is the right time for transition and that you are stable. Some of the things that we can help you with are:

- Helping you to set and achieve goals.
- Advising you about services available to you.
- Talking to other services, including your school, university, or workplace, on your behalf about health issues.
- Helping to liaise with other clinicians and keep everyone informed about issues you might be concerned about.
- Providing you and your family with relevant information about the transition process.
- Helping you learn more about your condition and to become more independent in developing strategies to manage your life as you move into college, university and/or work.

Medications

We will ensure that getting your medications will be a continual process when moving from paediatric to adult services which will be managed by Christine lupus nurse adult team. Lupus specific medications will initially be prescribed and provided by the adult lupus team with routine blood monitoring. For over 18-year-olds, as long as you are stable and depending on the medication you are on, we will request for your GP to take on blood monitoring and prescribing lupus specific medications. This process is known as 'shared care'. You will remain under the care of the adult team and continue to have routine follow up appointments with us.

Where are the adult services based?

The Rheumatology department is part of Liverpool University Hospital Foundation Trust (LUHFT). The Rheumatology department is split sites with Lupus services mainly at the Broadgreen Hospital site under the care of Dr McLaren (Consultant) and Christine Burton (Lupus Advanced Nurse Practitioner).

There is also a lupus service at the LUHFT Aintree site under Dr Benson (Consultant) in the connective tissue disease clinic, this is supported by Rheumatology nurses, in the Aintree team.

The site that you choose will be your main site and all your clinic appointments will be at this chosen site.

Broadgreen is based in main Rheumatology outpatient's department in the Alexandra Wing. Aintree clinic is based in Clinic F near the main tower block entrance.

Feedback

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

Further information

Please visit Liverpool University Hospital Foundation Trust website for further information including hospital addresses, site maps and getting here: https://www.liverpoolft.nhs.uk/our-hospitals

Broadgreen Lupus Telephone Advice Line: Monday – Friday 8.30am-4.30pm except Bank Holidays.

Lupus Tel: 0151 282 6047

Aintree Rheumatology Manned Advice Line: Monday – Friday 9.00am – 12.30pm except Bank Holidays.

Aintree Tel: 0151 529 3034

With being adult care, we prefer for the patient themselves to contact the advice line rather than a parent/guardian.

Information required when contacting is:

Full name

Date of Birth

Hospital or NHS number

Reason for contacting

Please remember to keep the contact details for your team in a safe place for when you need them.

Additional Useful Information

Websites for charity support groups and information

https://www.lupusuk.org.uk https://www.wrenproject.org/

Talking Therapies Support and self-referral:

Local services:

https://www.merseycare.nhs.uk/our-services/liverpool/talking-therapies

Young Person's Advisory Service age 5-25 Liverpool self-referral:

https://www.ypas.org.uk/

National services:

https://www.nhs.uk/mental-health/talking-therapies-medicine-treatments/talking-therapies-and-counselling/nhs-talking-therapies/

https://www.youngminds.org.uk/

Contraception and Sexual Health Clinics Merseyside self-referral:

Axess Service Merseyside:

Telephone Bookings 0300 323 1300

http://www.axess.clinic - online bookings

Liverpool

Royal Liverpool Hospital – Linda McCartney Centre Mon-Sat, see website for opening times – offer walk-in appointments and pre-booked.

The Beat, 6 David Lewis Street (behind Hanover Street) L1 4AP – Mon-Fri, see website for opening times – offer walk-in appointments and prebooked. Also offer axess 4 u (aged 19 and younger) walk-in Thurs only – see website for opening times.

South Liverpool Garston Treatment Centre, 32 Church Road L19 2LW – Mon-Fri, see website for opening times - pre-booked appointments only.

Knowsley

Huyton, The Arch 2 Ellison Grove L36 9GA – Mon-Fri, see website for opening times – offer walk-in appointments only on certain days and

pre-booked appointments. Also offer axess 4 u (aged 19 and younger) walk-in Weds only – see website for opening times.

Kirkby, St Chad's Health Centre, St Chad's Drive L32 8RE – only Weds – LARC only, see website for opening times.

St Helens

https://www.sexualhealthsthelens.nhs.uk/

Telephone bookings 01744 646 473 only for LARC. Walk in Mon-Fri 9.30am – 4.30pm.

Sexual Health St Helens, St Helens Hospital, Marshalls Cross Rd, St Helens, WA9 3DA – Mon-Fri as above, has under 19 service.

Sefton Sexual Health Services

https://seftonsexualhealth.nhs.uk

Telephone Consultation and booking 01695 656550 Mon-Thurs 9am-5pm, Fri 9am-4pm.

Bootle

St Hugh's (5th Floor), Stanley Rd L20 3QQ – Mon-Fri, see website for opening times – offer limited walk-in appointments and pre-booked appointments.

Southport

Southport Centre for Health & Wellbeing, Hoghton Street PR9 0PQ – Mon-Fri, see website for opening times – offer limited walk-in appointments and pre-booked appointments.

Author: Rheumatology Department

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All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

يمكن توفير جميع المعلومات المتعلقة بالمرضى الموافق عليهم من قبل ائتمان المستشفى عند الطلب بصيغ أخرى، بما في ذلك لغات أخرى وبطريقة مون والكترونيا.

所有經信托基金批准的患者資訊均可以其它格式提供,包括其它語言、 易讀閱讀軟件、大字

體、音頻、盲文、穆恩體(Moon)盲文和電子格式,敬請索取。

در صورت تمایل میتوانید کلیه اطلاعات تصویب شده توسط اتحادیه در رابطه با بیماران را به اشکال مختلف در دسترس داشته باشید، از جمله به زبانهای دیگر، به زبان ساده، چاپ درشت، صوت، خط مخصوص کوران، مون و بصورت روی خطی موجود است.

زانیاریی پیّو هندیدار به و نهخو شانه ی له لایه ن تراسته و پهسهند کراون، نهگه ر داوا بکریّت له فور ماته کانی تردا بریتی له زمانه کانی تر ، نیزی رید (هاسان خویندنه و)، جایی گهوره، شریتی دهنگ، هیلّی موون و نهلیّکترونیکی ههیه.

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Dhammaan warbixinta bukaanleyda ee Ururka ee la oggol yahay waxaa marka la codsado lagu heli karaa nuskhado kale, sida luqado kale, akhris fudud, far waaweyn, dhegeysi, farta braille ee dadka indhaha la', Moon iyo nidaam eletaroonig ah.