



Transitioning from Paediatrics to Adult Services when Living with Lupus

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Transition from Paediatrics to Adult Services

Becoming a young adult can be a time with many changes and opportunities, which can be exciting in some ways and challenging in others.

As you become a young adult, the children's hospital may no longer be the best place for you to have your treatment. As you are growing up, you may feel ready to move on to a more adult setting. Some people feel very ready for this, but, for others, it can be hard to leave behind the things they are familiar with and to move on to new places and challenges. This booklet is designed to better prepare young people for the process of transitioning to adult services from paediatrics.



transition

tran-zish-uhn

noun

Transition is the managed and coordinated process of transfer from paediatrics to adult care.

When will I transition to adult services?

The point at which care moves to an adult service is different for each person, which depends on various factors, such as:

- your current treatment
- how well you are at present (such as if you are in the middle of a flare)
- your life plans
- specifics of your local paediatric and adult services



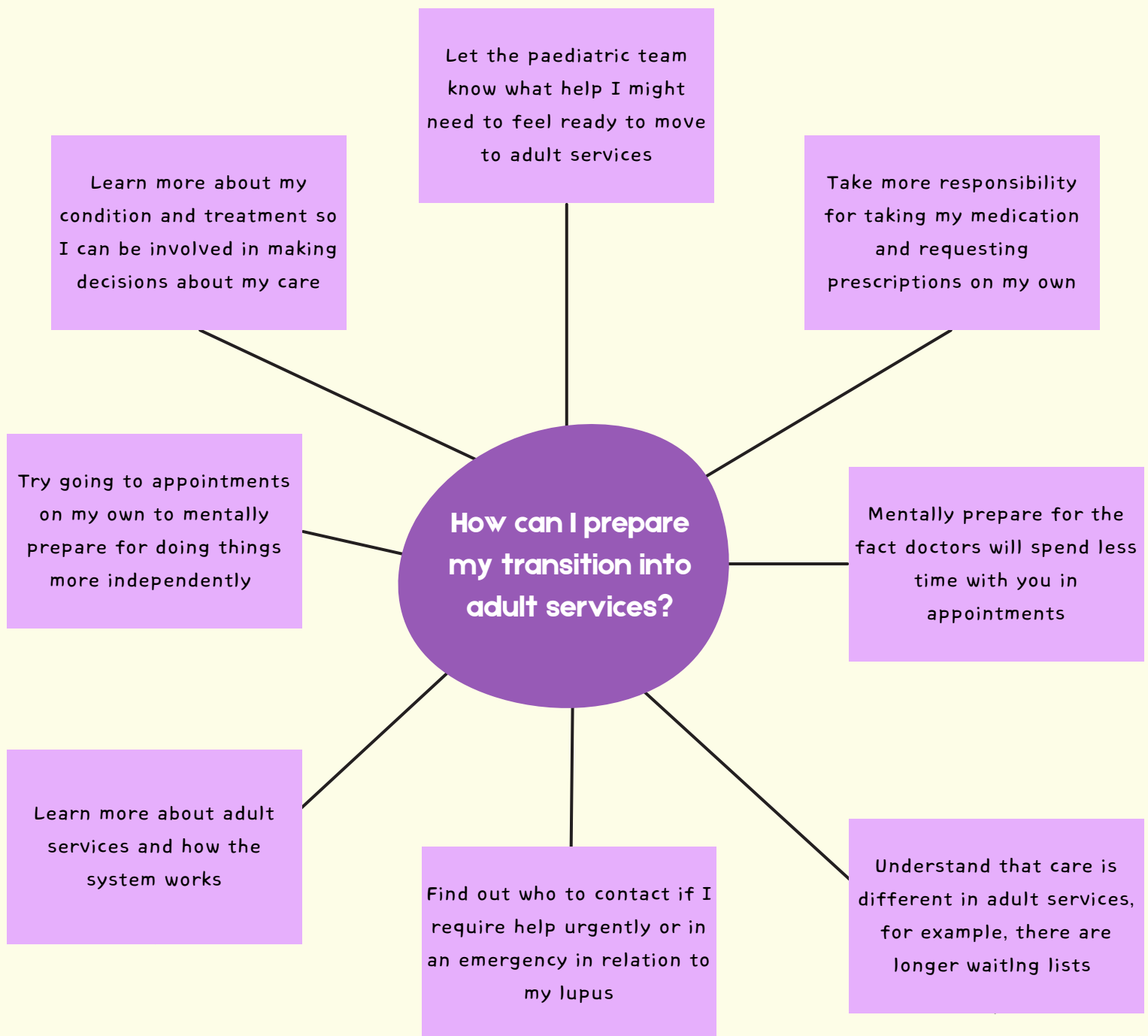
Effective transition is a vital part of your healthcare, so you should discuss the optimal time to do this with your medical team. It is a vital part of your healthcare because you will be changing from the medical teams who have been supporting you up to this point.



Transition from Paediatrics to Adult Services

What might Adult Services be like?

Adult services can be quite different to paediatric settings and it is important to be prepared and find out more about what adult services will be like. Some adult services have dedicated adolescent/young adult clinics designed to support young people move from children's services, but this is not always the case. You should consider various things that impact your transition from paediatric to adult services.



Transition - Knowledge and Skills in Healthcare



T-KASH was created by Alström Syndrome UK and Breaking Down Barriers to:

- draw attention to the knowledge and skills young people may be able to develop to manage their healthcare, while having the best life possible
- prepare young people/families for identifying and coping with change at key points in their lives
- support young people to plan for their future and cope with their eventual transfer/settling into adult services

The following pages used this model to help you think through your own transition journey to adult services.

Acknowledgement Statement:

T-KASH Transition Knowledge And Skills in Healthcare have been developed by young people with lived experience from Alström Syndrome UK, led by Marie McGee, National Transition Co-ordinator, ASUK. Further information can be found at www.breaking-down-barriers.org.uk/t-kash-transition-tools/



Transition from Paediatrics to Adult Services



Things I like doing, my wishes, getting on with people at home

What do I want to achieve and what support do I need to achieve this?

What do I want people to understand about my condition?

How I live through things I like; my language, and religion, the food I eat, clothes I wear and music I like



How can I wear the clothes I want to wear? Will I be safe in the sun?

How will the things I like support my transition journey?



Transition from Paediatrics to Adult Services



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What is important to me?

How will the things I like support my transition journey?



Transition from Paediatrics to Adult Services



Opening a bank account, managing money on a budget, planning my time, knowing where to go for more information

What financial decisions will I need to consider?

What resources could help support making these financial decisions?

Telling someone if I'm being bullied, being safe online and looking after myself when I'm out with friends



Who would I speak to if I was bullied or felt unsafe online?

How can I ensure I am safe both online and with friends?



Even when out with friends, remember to reapply sunscreen. Ensure your friends understand your situation.



Transition from Paediatrics to Adult Services



Going out with friends, doing things I like, having a laugh

What do I like doing? What makes me happy?

What support could help me live my best life living with lupus?

Looking after my emotions, knowing who to talk to and where I can go for help



Who can I go to for support about transition and to help me prepare?

Who would I talk to if I was unhappy about my healthcare plan regarding my lupus?



Transition from Paediatrics to Adult Services



Asking my own questions, seeing healthcare staff on my own, understanding my rights and responsibilities, making my own decisions

How can I prepare for appointments on my own?



When you are in adult services, you can still take people with you to appointments for support.



How would I explain my lupus to any new healthcare professionals?

Remember to take a medication list, with doses etc. and photos of symptoms to appointments

Healthy eating, exercise, shopping, cooking, getting around safely, and relationships



What support do I need for day-to-day activities? How can I receive it?



You can reach out to a team about managing day-to-day life

How and when would I explain my lupus to new people in my life?



Ask your specialist for foods to avoid or to include more of



Transition from Paediatrics to Adult Services



Being able to talk about my condition(s), describe how it affects my body and why I take medication and what it does

How can I describe how lupus affects me to my medical team?

Can I list medications/treatment that I am currently on and do I understand them?

Understanding my genetics and how genes are passed on



Genes are the building blocks in our body, carrying information about our characteristics like height or eye colour. Many health conditions are caused by a combination of having some genes that make you more likely to develop a condition (called “genetic predisposition”), and “environmental factors” like lifestyle, infections, hormones, and stress.

Some genes have been linked with lupus, but no particular gene or group of genes has been shown to cause lupus. This means there is no genetic test for lupus.

Lupus is likely caused by the interaction of genetic disposition and environmental factors. If a close family member has lupus, or another autoimmune condition, you may be more likely to develop lupus. However, most people with lupus don't have a family member with the condition.



For more information on genetics, visit RARE Youth Revolution's [My life, my genetics](#) videos



Transition from Paediatrics to Adult Services



Planning and preparing for big changes in my routine, including transferring into adult services and taking more responsibility for myself

Who will coordinate my transition process?



Think of questions that may concern you about your transition and work with your team to find solutions



What would I like to see in my transition journey from paediatrics to adult services?

If you don't hear about your referral to adult services, make sure you contact your consultant to follow-up

Becoming more independent, getting a good education, volunteering, finding work, developing life skills, having the best life possible



How will lupus impact my future education and employment?

What aids and adjustments can help me live the life I want to?

Further Information

<u>Mind</u>	http://www.mind.org.uk	Mental health service for those living in England and Wales
<u>Scottish Action for Mental Health</u>	http://www.samh.org.uk	Mental health service for those living in Scotland
<u>YoungMinds</u>	http://www.youngminds.org.uk	UK's leading charity fighting for children and young people's mental health
<u>Disability Rights UK</u>	http://www.disabilityrights.org	Influencing change for better rights, accessibility, benefits, quality of life, and economic opportunities for disabled people
<u>Disability Information Scotland</u>	http://www.disabilityscot.org.uk	Provide reliable, accurate, and accessible information for people living with disability(ies) in Scotland
<u>Citizen's Advice</u>	https://www.citizensadvice.org.uk/	Provides confidential information and practical advice to assist people with legal and health problems
<u>Patient Advice and Support Service</u>	https://pass-scotland.org.uk/	Service where you can share concerns, give feedback or comments, or make a complaint with NHS Scotland.
<u>Patient Advice and Liaison Service</u>	https://www.nhs.uk/nhs-services/hospitals/what-is-pals-patient-advice-and-liaison-service/	Service offering confidential advice, support and information on health-related matters in England and Wales
<u>Patient and Client Council</u>	https://pcc-ni.net/	Providing support and advice for any health concerns in Northern Ireland
<u>turn2us</u>	https://www.turn2us.org.uk/	Service providing information on benefits and financial support
<u>Scope</u>	https://www.scope.org.uk/	Providing practical information and emotional support to disabled people in England and Wales
<u>Kidscape and respect me</u>	https://www.kidscape.org.uk/ https://www.respectme.org.uk/	Kidscape is an bullying prevention charity in England and Wales and respect me for Scotland

Appointment checklist

Appointment type

Date

Location

Specialist:

Contact details:

Medication list and doses:

What do I need to prepare for the appointment?

Questions to ask:

Question:

Answer:

Question:

Answer:

Question:

Answer:

After appointment

Appointment checklist

Appointment type

Date

Location

Specialist:

Contact details:

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What do I need to prepare for the appointment?

Questions to ask:

Question:

Answer:

Question:

Answer:

Question:

Answer:

After appointment

Notes

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Important Contacts

Full Name	Contact

If you want more support from LUPUS UK, please contact us at headoffice@lupusuk.org.uk, or find us on:

<https://lupusuk.org.uk/> or <https://www.lupusukyouth.org/>



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