



Transition to Adult Rheumatology Care



McMaster
Children's
Hospital

HAMILTON HEALTH SCIENCES



What are the differences between pediatric and adult care?

| | Pediatric Care | Adult Care |
|--|---|--|
| Practice Approach | Family-centered; Parents very involved; shared decision making with parents | Patient-centered; Independence is strongly encouraged; shared decision making with young adult |
| Care Provider | Multi-disciplinary team members are involved with appointments | Clinic visits may include only the doctor and not a team of people |
| Clinic Location | In children's hospital | Private office-based settings or hospital clinic |
| Length of Appointment | Longer time | Shorter time |
| Parent/Caregiver Presence in Clinic | Parent/caregiver usually present during visit | Patient usually seen alone unless requests and consents to parent/caregivers presence |
| Information Sharing | Information shared with parents/caregivers | Information is shared with only the patient |

Resources and Contact Information:

Information about our projects:

www.canchild.ca/en/research-in-practice/current-studies

look for "TRUST Study"



What is “healthcare transition”?

“Healthcare transition” describes the gradual process of getting ready to transfer from pediatric to adult care around age 18.

- Introduction: The team will talk about the idea of transition and explore your youth’s skills, abilities and understanding of how to manage their health.
- Planning Process: With support from the pediatric team, the responsibility for your youth’s health care slowly shifts from you to the youth.
- Transfer: The time when your youth’s care will be shifted from the pediatric team to adult care.



Why is healthcare transition important?

Transferring from pediatric to adult care is a big change. This often comes at a time when there are many changes happening in a youth’s life. We want to encourage and support youth.

- Youth who feel supported through transition have more success and better disease control.
- If youth are moving away from home, they need support to become more independent in their care.
- If youth are uncomfortable, they might miss appointments, feel disconnected from their healthcare team, not take medication, and have more disease flares.



What is “self-management”?

We want youth to work towards being able to manage their health and life as independently as possible. This means that youth:

- know and understand their disease.
- are responsible for managing medicines and treatments.
- can independently take on everyday roles and responsibilities to manage their health.



What is my role in my youths’ transition?

It’s normal to feel emotions like fear, relief or even sadness as you begin to step back from managing your youth’s care. As a parent/caregiver, you may even feel excluded. It helps to be prepared by knowing about how things work in the adult healthcare system. Remember that even as your youth moves to independence, your support remains important to their success.

- Encourage, but don’t pressure, your youth to become independent with their medical care – this should be gradual, and every youth will move forward differently.
- Help your youth develop skills and be confident in communication, decision-making and self-care.
- Share or even hand-over responsibilities to your youth. This can be hard, but is important.
- Try to change your role from managing your youth’s care to supporting them and being a resource.



What is important for me, as a parent/caregiver, to know?

- The transition from adolescence to adulthood is a huge change for youth and caregivers.
- Brain changes that occur during adolescence affect decision making, planning, judgment, self-awareness and emotional control.
- Normal changes that occur during adolescence can be affected by the disease.
- Remember that every youth is different, handles this change differently, and experiences different changes.
- Risk-taking behaviours often increase during adolescence. Talking to healthcare providers about how these behaviours can impact disease and medications is important.
- Some youth will become more independent from caregivers at this time, while others may need support and guidance to become independent.
- Youth may develop more lifestyle and sexual identities that can be important to discuss with the healthcare team.





How can I encourage independence?

- Learn about the healthcare transition goals (see our RoadMap!)
- Support them through setbacks and challenges.
- Offer encouragement and let them know that it is important for them to achieve their goals.
- Be aware that this is a gradual process and that no one expects them to gain total independence overnight
- Work together with your youth through this process.



Who can I turn to for help?

- The entire healthcare team of pediatric and adult physicians, nurses, physiotherapists, and child life specialists are happy to help and answer questions!
- We have cheat sheets available if you would like them.
- Use the Youth Transition Road Map.

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