

Teens with chronic conditions face challenges and risks when they age out of pediatric rheumatology care

October 17 2022, by Michelle Batthish and Stephanie Garner



Credit: AI-generated image ([disclaimer](#))

Living with severe [inflammatory arthritis](#) or any other serious condition of the joints, bones and muscles is challenging for anyone, perhaps most of all for children. Young patients often experience pain, swelling and stiffness in many joints, which can limit their day-to-day activities.

Kids and teens with [chronic conditions](#), particularly those caused by [autoimmune disorders](#) like inflammatory arthritis, face special challenges as they painfully work their way through school and adolescence, which are already difficult enough.

But a special and highly unfortunate form of 18th birthday gift awaits these patients when they pass from the world of pediatric care and into the adult system.

Suddenly they enter a much, much larger pool of patients covering multiple generations, from [young people](#) like themselves all the way to the very elderly. It's a system that generally approaches all of them in the same way.

Aging out of pediatric care

Under pediatric care, patients with serious chronic conditions are wrapped in layers of care. Medical specialists skilled at treating and supporting young people work in team settings that also feature related forms of care, such as nursing support, physiotherapy and [child life specialists](#)—all with direct involvement from parents.

At 18 though, when these patients age out of the pediatric system, the scaffolding it provides falls away, leaving them to navigate—suddenly and without the engagement of their parents—an under-resourced adult system.

Both Dr. Garner (an adult rheumatologist) and I (a pediatric rheumatologist) have expertise in following youth with chronic rheumatic diseases, and work in transition clinics to help these patients complete a smooth transition. With the [Canadian Rheumatology Association](#) transition working group, we have recently written a [white paper on the problems this transition can cause](#). We have also included

our suggestions for how to improve the experience and the outcomes associated with it.

A vulnerable time of life

The changeover happens at a particularly vulnerable time of life, when these patients are also going through so many other major changes, such as entering university or college, living independently, dating and relationships and making choices about drinking and recreational drugs.

It's a time of life when many also lose the coverage of their parents' medical benefits. This can make it more challenging to access medication, which increases the chance they will simply stop taking it and become vulnerable to severe complications.

It's also a stage of development when [mental health](#) is a particular concern, more so for young patients because [rates of anxiety and depression are already elevated among people with chronic illnesses](#).

On the clinical side of the equation, young adult patients require more time on average than patients who have lived longer with their chronic illnesses. They also come with more non-medical issues, such as psychosocial, educational and vocational needs. Many adult rheumatologists feel the non-medical side of their care is better handled by [family physicians](#), but the reality is that family doctors may not have much time, either.

[Mental health care](#) and other supports are available to young adult patients, but in more of an à la carte model and, frequently, with long waits. As they enter the more crowded, resource-strapped environment of adult care, that is just the time when young patients may need those supports most.

Challenges for rheumatologists and patients

Further complicating matters, adult rheumatologists are not specifically trained for—and may not have experience with—young patients coming out of the pediatric system. They need to understand more about the adolescent brain, their maturity and how they can shape [young patients'](#) perceptions and behaviors.

It may not be easy asking younger patients about certain topics like drinking, recreational drugs or sexual activity. It can also be hard to tease out if these patients are taking their medications as prescribed.

Some of the hard realities of passing into adult care are beyond easy or fast repair, but we can do more to prepare pediatric patients for the transition. This includes strengthening their self-management and self-advocacy skills and increasing their awareness of how things will change when they enter the adult health-care system.

Some transition programs are excellent, but that is far from universally true, especially outside of major cities that often have children's hospitals. In some areas, there may be no support available at all.

The transition from [pediatric care](#) should not end with the first visit to an adult rheumatologist. More supports are also needed on the adult side to make the transitions more durable.

Taking on adult responsibilities is hard. Living with arthritis and its constellation of related conditions is harder. Expecting teenagers to face both independently in the adult health-care system is not fair.

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