

# Pediatric-to-Adult Care in Rheumatology

By Angela How, MD, FRCPC

The definition of successful transition of care for youth consists of the development of the skills to manage one's own healthcare and to avoid irreversible disease-related damage. Transfer of care is the act of moving from pediatric care to adult care.

Before the early 2000s, pediatric-to-adult care transition was underdeveloped, despite the fact that 90% of children with chronic health issues survive into adulthood.<sup>1</sup> In 2010, the Montreal Children's Hospital reported that 52% of patients with juvenile idiopathic arthritis (JIA) did not transfer successfully to adult care<sup>2</sup> despite the fact that 50% of JIA patients still had active disease at the time of transfer.<sup>1</sup> Poor transition increases the risk for morbidity, mental health challenges, suboptimal vocational outcomes, etc.

Adolescents face physical and psychosocial developmental challenges as they transition to independence, often hindered by excessive parental involvement. Successful transition can be supported by appropriate healthcare beyond the pediatric setting.

Over the past twenty years, increasing awareness of these challenges led to the development of guides to improve successful transitioning. Got Transition<sup>3</sup> and The American College of Rheumatology Transition Toolkit<sup>4</sup> provide foundational and best practices curricula. Despite this, a survey of US adult rheumatologists in 2018 found that 45% were never trained in transition practices, only 56% felt comfortable caring for former pediatric patients, and 37% did not have a plan for transitioning young adults into their practices.<sup>5</sup>

British Columbia is a leader in transition services in rheumatology. Pilot transition programs for young adults with spondyloarthritis and autoimmune diseases were offered in 1988! In 1993, Dr. David Cabral, a pediatric rheumatologist, and Dr. Stephanie Ensworth, an adult rheumatologist, combined these clinics and included patients with other inflammatory diseases such as JIA



into the Young Adults with Rheumatic Diseases (YARD) clinic. This was located in the Mary Pack Arthritis Centre and was supported by the Arthritis Society. Dr. Angela How took over as the adult rheumatologist in 1998. There are now four pediatric and three adult rheumatologists associated with the YARD clinic.

The YARD clinic model is shared care with pediatric and adult rheumatologists and fellows, a nurse coordinator, a social worker, an occupational therapist, a physiotherapist, and clerical staff. Timely access to mental health services, vocational and sexual counselling, and a network of youth-friendly adult spe-

cialists (e.g., ophthalmology, orthopedics, nephrology, etc.) is also provided.

The clinic promotes independence, acquisition of disease and treatment knowledge, and readiness for transfer.<sup>6</sup>

**The determinants of readiness to transition include the patient having:**

1. Adequate knowledge of the disease, with their treatment choices being balanced and informed
2. Skills to negotiate the healthcare system and manage their health needs
3. An independent adult relationship with the health care system
4. A family doctor and the ability to advocate for themselves regarding their health

The average time of transfer to adult care is around 20-21 years of age. If the patient is not ready by age 22, the feeling is that more time in the YARD clinic is unlikely to be helpful.<sup>6</sup>

Transfer to an adult rheumatologist can be more challenging if the young adult lives in a remote or rural area, moves for education, or plans to travel to other parts of Canada and beyond. This takes extra planning and time. The patient needs to be coached on what steps to take if a health complication occurs.

In a 2018 survey of 46 youth being seen in the YARD clinic, 76% completed the questionnaire. Some of the results were as follows:

1. 95% were satisfied with the care they received
2. 75% liked not having their parents attending their clinic visits except for transport when necessary. They felt this encouraged them to take more responsibility for their health.
3. 25% requested more information on drug and alcohol use and mental and sexual health services

In answers to open-ended questions, the top positive aspects of our transitional clinic were:

1. Friendly and welcoming staff
2. Continuity from pediatric care
3. Availability of a nurse to contact outside clinic hours

Negative aspects included the following:

1. The need to travel to a centralized clinic which, for some patients, required flights from more remote areas of BC
2. Long wait times in the clinic on occasion

Data from a 2025 YARD survey are still being processed. Here are some positive comments to open-ended questions:

1. "The team speaks to me about my disease and medication in a way that I can easily understand."
2. "Since coming to the clinic I have found it easier to take my medications and to stay on treatment."
3. "I like that my parents are not in the room at clinic visits."
4. "I feel confident to see an adult rheumatologist."

There were also a few negative comments:

1. "I fear I will give up on 'self-support' and need more lessons to keep track of the disease (sic)"
2. "I prefer to see the same doctor at every visit."
3. "The time I spend in the waiting room is too long."

We plan further follow-up studies to track these young adults as they transition to exclusively adult care, made easier as the three adult rheumatologists in the YARD clinic have accepted the majority of transfers from YARD.

I have included one other reference that is an excellent review of the transition and transfer process.<sup>8</sup>

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