

Transition of Care in Rheumatology: A Long and Winding Road to Achieving Successful Transition of Care

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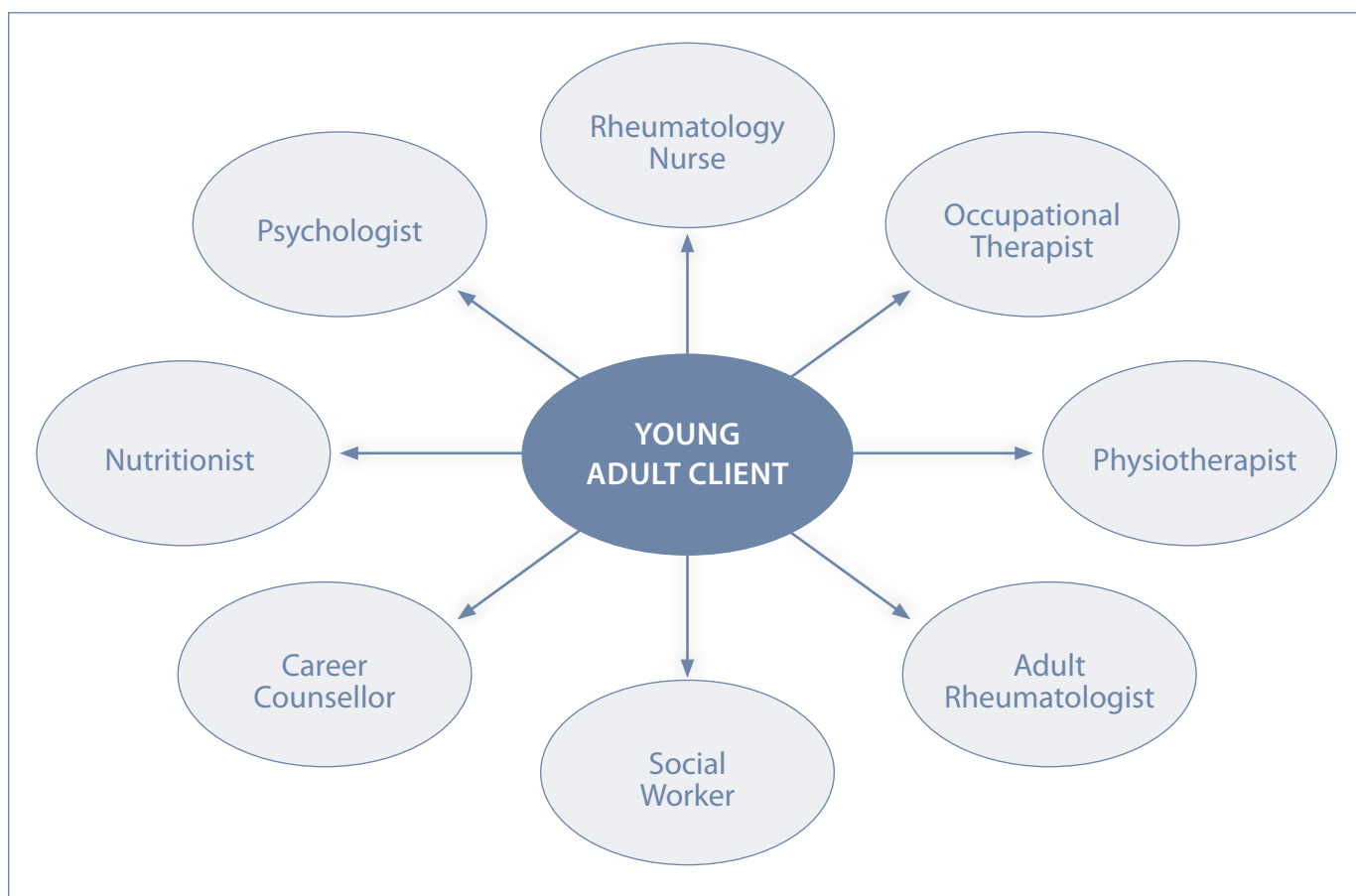
After completing a fellowship in adolescent medicine and issues of Transition in Young Adults with Rheumatic Diseases (YARD) at the University of British Columbia (UBC), McGill and *Université de Montréal*, I brought my expertise back to McGill. My fellowship research project examined young rheumatology patients who graduated from the Montreal Children's Hospital and were transferred to adult rheumatologists in the McGill network. The study demonstrated that over half of these patients were not receiving the necessary care they needed because they could not navigate the transition period to an adult hospital. Many were lost to follow up despite having severe systemic diseases and ended up in emergency rooms with flares of their diseases and accumulated irreversible damage.

After identifying that this patient population requires special treatment and guidance in order to integrate themselves into the adult healthcare system, we embarked on designing a better transition experience for these young adults. The YARD clinic was opened in 2007 at the Montreal General Hospital (MGH) where over 250 patients are

now followed annually. This clinic allows for more flexible appointment scheduling and patients have the support of our rheumatology nurse. The goal of the YARD clinic is to give young adults agency and autonomy through understanding their diseases, and the medications and non-medical approaches to managing their symptoms.

Despite the rapid growth of the YARD clinic, we soon realized its limitations. Unlike at the Children's Hospital, my patients had very limited access to occupational therapy, physical therapy, social work and psychology services. After exploring many different avenues, we helped to create a specialized multi-disciplinary program at the Constance-Lethbridge Rehabilitation Centre. We worked together with other healthcare teams and realized that there are common issues in the transition of care for young adults with chronic diseases, and we were able to leverage some of those services. We created a program that both evaluates the young adult's preparedness for transition to adult care and helps them to achieve greater independence in their daily activities, by providing them the tools to navigate school, work, leisure, home, and family life.





This program was successful, but only a minority of eligible patients were accessing it. Therefore, in 2016, I collaborated with my colleagues in pediatric rheumatology to change the way that we transition patients from the Montreal Children's to the adult clinic at the Montreal General Hospital (MGH). All eligible 17-year-olds are first seen at a transition clinic at the Constance Lethbridge Centre, which is attended by myself, the Children's Hospital rheumatology nurse, the Centre's program coordinator, physiotherapist and social worker as well as the patient's parent(s). The focus of this clinic is on the non-medical aspects of the patient's care, and the team gets a good idea of each teenager's limitations and goals. The team develops an individualized treatment plan for each young adult (See Figure 1). A few months later, we complete the transfer of care with the patient's first medical visit at the MGH.

The initial feedback from patients and parents was very positive. We noticed improved physical function, medication compliance and disease outcomes for those young adults who had taken advantage of the resources. But many of our clientele did not see the necessity of the rehabilitation program, especially if their arthritis was under control.

In 2023, we modified the program and added a career counsellor to our team. She meets with every client and assists them in planning their studies and careers. Both parents and patients have commented on the importance of addressing this important facet of their lives.

In 2024, we repeated the study on the transition process, and our rate of success climbed to almost 90%. It truly takes a village to support youth with chronic diseases. I am incredibly lucky to have a wonderful team.

References:

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