

TRANSITIONING TO ADULT RHEUMATOLOGY CARE: A GUIDE FOR YOUNG ADULTS AND THEIR FAMILIES

by Rebecca E. Sadun, MD, PhD, and Esinam Bediako



The transition from adolescence to adulthood involves navigating newfound life skills, forging one's identity, and establishing independence. However, young people with conditions like spondyloarthritis face an additional milestone: the shift from pediatric to adult rheumatology care and the need to assume personal responsibility for one's health. The process involves adapting to new healthcare providers, treatment plans, and support systems tailored for adult patients, while simultaneously developing self-management skills.

Around half of young adult patients with childhood-onset rheumatic diseases do not maintain consistent follow-up within the first year of transitioning to adult rheumatology care.¹ Preparing for the transition could help to ensure that more young adult patients continue to get the treatment they need as they age out of pediatric care.

When Should Adult Care Begin?

Most rheumatology patients diagnosed during childhood will transfer from pediatric to adult rheumatology care between the ages of 18 and 23 years old. The most appropriate time varies, however, based on where a patient receives medical care and depends on certain patient factors. Disease complexity, treatment requirements, active symptoms, and the availability of specialized adult rheumatology services in the area all may play a role in determining the timing of the transfer. Insurance coverage and provider availability can influence the practical aspects of the transfer as well. Experts advise families to discuss transfer circumstances at least 2 years before the time of transfer in order to make a plan that is optimized for both patient factors and logistical factors. This lead time also enables for the identification of an appropriate adult provider and the development of pre-transfer goals.

Differences between Pediatric and Adult Rheumatology

Some might assume that transferring to adult rheumatology care is just a matter of finding a new doctor. In fact, there are many differences between pediatric and adult care, and sometimes these differences dissuade young people and their parents from pursuing ongoing care with an adult rheumatologist.

Pediatric rheumatology clinics are designed to be child-friendly, often featuring bright colors and games to create a welcoming environment. They often offer multidisciplinary care, with social work, physical therapy, and child life specialists available to optimize patient care and reduce the number of clinic appointments for patients and their families. Pediatric rheumatology practitioners engage patients in discussions about educational and personal goals, leading to the young adult feeling connected. Clinics in pediatric rheumatology typically have longer visits, allowing for more comprehensive physical exams. Pediatric practices may also be better able to accommodate late arrivals or fit patients in for urgent appointments. There is also more of a goal of care of achieving complete remission and then attempting to wean medications.²

In contrast, adult rheumatology practices tend to be more austere, lacking the child-friendly elements found in pediatric rheumatology offices. Ancillary services such as social work and physical therapy are less commonly available on-site, and clinic visits are often shorter with more strict enforcement of arrival time cutoffs and no-show policies. Low disease activity may be tolerated, and treatment approaches may involve steroid tapers for intermittent flares. Finally, if several unsuccessful attempts have been made to wean a patient off of care, the adult rheumatologist is likely to recommend lifelong treatment, which is often required for effective care of adult patients.² For more information on differences between pediatric and adult rheumatology, see bit.ly/rheum_transition.

Steps Families Can Take to Prepare for the Transition

The differences between pediatric and adult practices can sometimes alienate young adults and their families. However, with awareness and preparation, the transition can be smoother. Here are some ways young patients and their families can get ready.

- Start preparing two years before the anticipated transfer date, allowing time to address any health insurance changes, set and achieve self-management goals, and schedule an appointment with an appropriate new adult rheumatology provider.
- Seek to transfer during a time of medical and social stability (e.g., a young adult moving away for college or a new job might consider transferring care sometime before or after the move, rather than coinciding with the move, providing the patient an opportunity to adapt to a new rheumatologist and a new environment at separate times, to reduce the likelihood of overwhelm).

- Consider different care models for students attending college away from home, such as establishing with a local adult provider, but also continuing care with the existing pediatric rheumatology provider during school breaks, using telehealth, or both.
- Encourage independence in self-management before the young adult patient leaves home. A young patient should practice scheduling and keeping track of appointments, refilling and taking their medications, and following through with treatment recommendations.
- Register with the college's Office of Disability Services (this office may have different names at different institutions) for accommodations under Section 504 of the Rehabilitation Act and the Americans with Disabilities Act. This will enable flexibility if the patient has a flare during the college semester.
- Ask if your pediatric provider can send transfer documentation to your new adult provider to help them understand the medical history. The American College of Rheumatology offers templated medical summary forms specifically for patients with rheumatologic diagnoses: bit.ly/rheum_transition_2
- Ensure continuity of care by continuing with pediatric rheumatology appointments until the first scheduled adult rheumatology appointment and by obtaining sufficient medication refills before the transfer.²

Further Support

Effective communication is key in ensuring a seamless transition from pediatric care to adult care. Resources provided by organizations like Got Transition and the American College of Rheumatology can offer invaluable support to young patients, parents, caregivers, and clinicians during this process. Additionally, maintaining open communication with your pediatric rheumatologist is crucial, as they can help you develop an effective transition plan tailored to your specific needs. Working together as a team, the transition to adult care can be smooth and successful.



1. Hart LC, Pollock M, Brown A, et al. Where did they go? Tracking young adult follow-up during the transition from pediatric to adult-oriented care. *Clin Pediatr (Phila)*. 2019 Oct;58(11-12):1277-1283.
2. Sadun RE, Covert LT, Lawson EF. Transitioning to Adulthood with a Rheumatic Disease: A Case-Based Approach for Rheumatology Care Teams

