

Primary Ciliary Dyskinesia: A Suggested Pathway to Transition From Pediatric to Adult Care

Research Summary



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Key Take-Home Message for Patients & Families

Transitioning from pediatric to adult healthcare is an important process for young people with PCD, and it should begin well before they leave pediatric care. The goal is to gradually help teens develop the knowledge, skills, and confidence to take greater responsibility for their health and communicate directly with their healthcare team. Pediatric and adult providers should work together, when possible, to support this process and help ensure care continues without interruption.

What did this study look at?

This study examined how pediatric care teams can better prepare young people with Primary Ciliary Dyskinesia (PCD) to transition smoothly from pediatric to adult healthcare settings.

What was the research question?

What practical, structured pathway can medical teams follow to help youth with PCD build self-management skills and safely transition into adult care?

Who took part in this study?

Pediatric and adult pulmonology specialists, along with an Internal Medicine-Pediatrics trainee and a pediatric psychologist, wrote this clinical recommendation paper. The parent of a teenage patient with PCD reviewed it, and the authors incorporated her recommendations. Rather than enrolling

patients in a trial, the authors gathered current evidence and best practices in PCD care to design a guided transition framework.

Because healthcare systems and resources vary by location, not every clinic will offer the same setup or resources described in this recommended framework.

What were the results?

The authors outlined a step-by-step transition pathway designed to start early in adolescence and continue into young adulthood. The core findings and recommendations include:

- **Starting Early:** Beginning discussions around age 12–14 to build knowledge and self-care independence gradually.
- **Skill Building:** Helping teens learn their medications, understand their lung function results, and practice speaking directly with their care team.
- **Joint Care Planning:** Utilizing joint visits or direct communication between pediatric and adult PCD experts to make the handoff as seamless as possible.

What are the conclusions?

Having a formal, structured transition protocol helps ensure young people with PCD do not experience gaps in specialized care or airway clearance management as they enter adulthood.

What are the considerations?

There are some important limitations to keep in mind:

- The paper proposes a suggested pathway based on expert guidance rather than a randomized study measuring patient outcomes.
- Individual readiness varies significantly—age alone should not dictate when a young person transfers to adult care.
- Differences in local clinic resources and/or insurance coverage may require healthcare teams to adapt the pathway for individual patients.
- Future studies will focus on looking at transition pathway implementation outcomes.

Citation

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Disclaimer

Research in a rare disease like PCD is an important part of moving the field forward. Sometimes research findings are encouraging; other times they may seem confusing, disappointing, or concerning. Because research is continually advancing, a single paper rarely tells the whole story. Remember that every person with PCD is unique, and research findings and recommendations do not always reflect what an individual will experience. If a paper raises questions or concerns for you, talk with your healthcare provider. They can help you understand what the information means—and what it may not mean—for you or your family member.