



DR. PAUL TURNER (Orcid ID : 0000-0001-9862-5161)

Article type : Editorial

EDITORIAL for ALL-2020-00672

TITLE: From child to adult: putting the patient first and foremost

Margaux Couffon^{1*}, Ella Stoneham^{1*}, Paul J. Turner²

*Joint first authors

Affiliations:

¹Patient within Paediatric Allergy Services, Imperial College Healthcare NHS Trust, London, UK;

²Section of Inflammation, Repair and Development, National Heart & Lung Institute, Imperial College London, London, UK.

*Corresponding author:

Dr Paul Turner

Section of Inflammation, Repair and Development,

This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the [Version of Record](#). Please cite this article as [doi: 10.1111/all.14515](https://doi.org/10.1111/all.14515)

This article is protected by copyright. All rights reserved

National Heart & Lung Institute,
Imperial College London,
Norfolk Place
London, W2 1PG

Tel: +44 (0)20 3312 7754

Email: p.turner@imperial.ac.uk

Word Count: 931

CONFLICTS OF INTEREST:

Dr. Turner reports grants from UK Medical Research Council, NIHR/Imperial Biomedical Research Centre, End Allergies Together, Jon Moulton Charity Trust, grants and personal fees from the UK Food Standards Agency, personal fees from DBV Technologies, Allergenics, ILSI Europe, personal fees and non-financial support from Aimmune Therapeutics, outside the submitted work. The other co-authors are patients of Imperial College Healthcare NHS Trust, and do not have any conflicts of interest.

“I would hold your hand every minute of every day,
But I won't because I know you need to find your own way.”

- Jayne Sena¹

When does a child become an adult? Transition does not happen at a particular instance, yet many health systems are poorly designed to acknowledge that transition from childhood to adult is a process which occurs over many years, as highlighted in this issue by a new Guideline from the EAACI Task Force on Adolescents and Young Adults.² In many clinics in Europe, “paediatrics” stops at age 16 – at the very time when young people are undergoing the greatest changes in their lives. It is therefore not surprising that the World Health Organisation defines “young people” to include adults up to age 25 years.³

As young adults with atopic disease become more independent, they need to take more responsibility in terms of carrying allergy treatments with them (and using them!), and being able to deal with the risk and reality of asthma exacerbations and accidental reactions to food allergens. This increasing responsibility can be overwhelming for a teenager having to deal with increasing school stresses and changes in social life. At the same time, it can be quite daunting for a young person to transition into a different clinical service, so attempts to run children's and adult services in parallel, in conjunction with each other, are to be encouraged. Unfortunately, the evidence base for interventions to improve self-management in this age group is limited, particularly with respect to food allergy.⁴

Transition is a process – and needs to be gradual and tailored as much as possible to the individual. Many young people do not really know what they want when transitioning. For one of us, it was only later that “I realised this is a time when I've needed more support than I probably expected. Lots of things changed in a really short period of time, a very different type of social life, holidays without parents, going to university and working. I have had to learn a whole different set of skills to keep myself safe, which has been really hard at times, to learn to manage my allergies and my anxiety over them in completely new contexts - lots of them very simple situations that my friends probably wouldn't think twice about, but for me could be life threatening.”

Given that allergic conditions have a very significant adverse impact on health-related quality of life in adolescents, which in turn can have severe impacts on mental health and well-being,⁵ it is essential that we are able to help our patients – while at the same time, optimising the clinician time needed to achieve this. A number of tools exist, such as the Transition Readiness Assessment Questionnaire⁶ or “Ready, Steady, Go”,⁷ which allow a joint assessment of each young person’s needs and how this changes during transition. Transition needs to respond to the needs of the individual, and must take into account factors like the patient's confidence in managing their allergies, other health issues and the level of school and social life stresses.

The process of transitioning patients with allergic disease is not unique: there are many features in common with other specialties: the challenges of being accepted by peers, how to explain their health conditions to others. Young people with long-term health conditions often feel different – and alone – so transition is an opportunity for our patients to meet with their peers, for them (and indeed ourselves) to share experiences and gain support from one other.⁵ Our own experience is that we would have loved to meet others like us, going through the same experiences, struggling with the same challenges – and having an opportunity to share our experiences and concerns – not necessarily, and probably not with, a doctor. A longer transition or more targeted support would have been really helpful, together with having someone to contact, and not just an annual review that focuses on the clinical management of my symptoms but does not provide support to overcoming the real-world challenges experienced in between appointments. Healthcare professionals should consider building links with transitioning services for other clinical diseases, which might perhaps aid negotiations for improved local provision within a multidisciplinary team.

In many health systems, primary care has a crucial role in providing allergy care – particularly in adult services – yet primary care professionals are rarely involved in the transition process.⁸ From personal experience, young people often feel their family doctor is separate to their allergy team, something not helped by a perception that the role of primary care is primarily for prescriptions (something which is often unnecessarily complicated by process and, for example, restrictions on prescribing (pertaining to, for example, adrenaline auto-injectors)). Yet failings in

the communication between primary care and hospital teams represent an important risk factor in asthma fatalities.⁹ Hospital-based teams need to build strong links to primary care, and ensure engagement both amongst healthcare professionals and with the young person, who must learn to understand the important role of primary care in adult services.

There is much still to learn: results from a 5-year study on transition funded by the UK National Institute for Health Research concluded that of nine proposed features to facilitate transition, only 3 appeared to result in improved outcomes: appropriate parent involvement which changes accordingly during transition; promotion of health self-efficacy; and interaction with the “adult” team.¹⁰ We should all embrace the EAACI guideline but also strive to evaluate the success of its recommendations so we can bring more evidence to transition practice when the guideline is updated in 5 years’ time.

REFERENCES

1. Jayne Sena. "What I Would Do For You." Family Friend Poems, Feb 2006.
<https://www.familyfriendpoems.com/poem/mother-to-child-poem-what-i-would-do-for-you>
2. Roberts G, Vazquez-Ortiz M, Knibb R, et al. EAACI Guideline on the effective transition of adolescents and young adults with allergy and asthma. Allergy 2020 Jun 19. doi: 10.1111/all.14459.
3. World Health Organization. Engaging young people for health and sustainable development. Geneva: WHO, 2018. Available at: <https://www.who.int/life-course/publications/engaging-young-people-for-health-and-sustainable-development/en/> [Accessed 1 July 2020].
4. Knibb RC, Alviani C, Garriga-Baraut T, et al. The effectiveness of interventions to improve self-management for adolescents and young adults with allergic conditions: a systematic review. Allergy 2020; doi: 10.1111/all.14269.

- Accepted Article
5. Vazquez-Ortiz M, Angier E, Blumchen K, et al. Understanding the challenges faced by adolescents and young adults with allergic conditions: a systematic review. *Allergy* 2020; doi: 10.1111/all.14258.
 6. Sawicki GS, Lukens-Bull K, Yin X, et al. Measuring the transition readiness of youth with special healthcare needs: validation of the TRAQ--Transition Readiness Assessment Questionnaire. *J Pediatr Psychol*. 2011;36(2):160-171.
 7. Nagra A, McGinnity PM, Davis N, Salmon AP. Implementing transition: Ready Steady Go. *Arch Dis Child Educ Pract Ed*. 2015;100(6):313-320.
 8. Han, A.X., Whitehouse, S.R., Tsai, S. et al. Perceptions of the family physician from adolescents and their caregivers preparing to transition to adult care. *BMC Fam Pract* 2018;19, 140.
 9. Levy ML, Garnett F, Kuku A, Pertsovskaya I, McKnight E, Haughney J. A review of asthma care in 50 general practices in Bedfordshire, United Kingdom. *NPJ Prim Care Respir Med*. 2018; 28: 29. doi: 10.1038/s41533-018-0093-7
 10. Colver A, Rapley T, Parr JR, et al. Facilitating transition of young people with long-term health conditions from children's to adults' healthcare services - implications of a 5-year research programme. *Clin Med (Lond)*. 2020;20(1):74-80.