## Adolescents with chronic disease

## Sarah Mansfield

They were the age staring down the barrel not of Is anything true but of Am I true, and What am I, of What is this thing, and it made them strange.<sup>1</sup>

The theme for this issue is chronic illness in adolescents. However, determining exactly who this theme refers to is tricky. The boundaries of adolescence are heavily culturally defined. It is difficult to find agreement on a simple, aged-based characterisation or a biological definition based on the process of puberty; both fail to capture the complexity of this transition period from child to adult. Indeed, the very existence of adolescence as a universal developmental stage is debated. This definitional uncertainty is perhaps not unrelated to that being experienced by young people themselves during this stage - am I true, and what am I?

Interestingly, despite (or perhaps because of) living in a phase of relative flux, adolescents have been shown to have a higher degree of tolerance for uncertainty and ambiguity than children or adults.<sup>2</sup>The uncertainty and ambiguity associated with adolescents may actually be more challenging for their general practitioners (GPs), who can view adolescents as 'different' from other patient groups.<sup>3</sup> Evidence shows that many GPs lack confidence in working with adolescents, citing insufficient expertise, particularly with communication and relationship development.<sup>4,5</sup>

Adolescents who have or who develop a chronic health condition can pose additional challenges for GPs. The condition itself or its treatment may have an impact on the young person's physical, psychological and social development, while their stage of development may in turn influence the presentation and progression of the condition.<sup>6.7</sup> In this issue of *Australian Family Physician (AFP)*, Wilson provides readers with very relevant and practical skills to build their confidence.<sup>8</sup>

While many GPs are likely to have experience with conditions such as type 1 diabetes and asthma in young people, this issue of *AFP* also provides updates on less familiar but important chronic conditions that may emerge in adolescence. Ellims discusses hypertrophic cardiomyopathy,<sup>9</sup> Tiller and Allen explore rheumatological problems,<sup>10</sup> and Grover, De Nardi and Lewindon review inflammatory bowel disease,<sup>11</sup> all covering the particular diagnostic and management challenges that occur in adolescents.

Finding authors and peer reviewers for these topics was difficult, illustrating their highly specialised nature. Many of the clinicians we approached specialised in either young children or adults, but nothing in between. It is perhaps unsurprising then, that young people with chronic illnesses frequently experience worsening health outcomes following the inevitable graduation from comprehensive paediatric care into what are often patchier adult models of care. This has been attributed, at least in part, to lack of access to services that are responsive to their needs.<sup>4,12</sup> To address this, some tertiary services have developed specialised adolescent services, and there is now a paediatric subspecialty in adolescent medicine, and some limited community-based services with clinicians who have a special interest in adolescent health. However, not all young people have access to such services, particularly those in rural and regional areas.

GPs are uniquely placed to assist in bridging this gap by being a constant presence in the lives of young people with chronic illnesses. While some GPs have taken a special interest in adolescent and youth health, many of us, as noted, feel inadequately prepared for this role. This suggests that greater focus on this area of medicine in fellowship training is warranted, as well as more opportunities for GPs to engage in relevant professional development activities. Through such initiatives, we can better support our adolescent patients as they navigate both the everyday challenges young people can face and their chronic health conditions.

## Author

Sarah Mansfield FRACGP, MBBS (Hons), MSc, DCH is a medical editor at *AFP*, senior lecturer in academic general practice at Deakin University, and a general practitioner in Point Lonsdale, Vic.

## References

- . Wallace DF. Infinite jest: A novel. New York City: Little Brown and Company, 1996. p. 1070.
- van den Bos W, Hertwig R. Adolescents display distinctive tolerance to ambiguity and to uncertainty during risky decision making. Sci Rep 2017;7:40962.
- Roberts J, Crosland A, Fulton J. GPs' responses to adolescents presenting with psychological difficulties: A conceptual model of fixers, future planners, and collaborators. Br J Gen Pract 2014;64(622):e254–61.
- Kang M, Bernard D, Usherwood T, et al. Towards better practice in primary health care settings for young people. Health Promot J Austr 2006;17(2):139–44.
- Kang M, Bernard D, Usherwood T, et al. Primary Health care for young people: Are there models of service delivery that improve access and quality? Youth Studies Australia 2006;25(2):49–59.
- Sawyer SM, Drew S, Yeo MS, Britto MT. Adolescents with a chronic condition: Challenges living, challenges treating. Lancet. 2007;369(9571):1481–89.
- Sawyer S, Drew S, Duncan R. Adolescents with chronic disease – The double whammy. Aust Fam Physician 2007;36(8):622–27.
- Wilson EV. Engaging young people with a chronic illness. Aust Fam Physician 2017;46(8):572–76.
- Ellims AH. Hypertrophic cardiomyopathy in the adolescent. Aust Fam Physician 2017;46(8):553–57.
- 10. Tiller G, Allen R. Rheumatology and the adolescent patient. Aust Fam Physician 2017;46(8):558–63.
- Grover Z, De Nardi A, Lewindon PJ. Inflammatory bowel disease in adolescents. Aust Fam Physician 2017;46(8):565–71.
- Perry L, Steinbeck KS, Dunbabin JS, Lowe JM. Lost in transition? Access to and uptake of adult health services and outcomes for young people with type 1 diabetes in regional New South Wales. Med J Aust 2010;193(8):444–49.