

## Chronic illness in adolescents

THIRTY YEARS AGO, Pless and Pinkerton<sup>1</sup> highlighted the fact that, although children and adolescents experience a diverse range of illnesses, those with chronic conditions have great similarities in their life experiences and in the preventive and rehabilitative aspects of their lives. Since then, the intensity of treatment programs recommended for managing adolescent chronic illnesses has increased greatly. As a result, the daily lives of adolescents with chronic illness are often very different from those of their healthy peers.

Adolescents with a chronic illness have usually lived with the illness for much of their lives. Although there is generally no prospect of a cure, they have to complete time-consuming and inconvenient treatment tasks every day. Treatment regimens now recommended for managing chronic illnesses are intensive and often tedious, but there is evidence that they can lessen the impact of some disorders (eg, in adolescents with diabetes, good metabolic control is associated with better quality of life).<sup>2</sup> As adolescents take over management of their illness from their parents, they have to decide to what extent they will comply with treatment. Young people who develop a chronic illness during adolescence often have difficulty accepting their illness, and treating them can be quite a challenge for physicians.

In a recent two-year prospective study of chronic illness conducted by our group,<sup>3</sup> we found that adolescents with diabetes did not consider the restrictions on their regular food or drink intake a large inconvenience. However, managing their illness (including injecting insulin and monitoring blood glucose levels) took them an hour a day, on average. Adolescents with cystic fibrosis spent even longer (1.5 hours a day) managing their illness: typically, they began each day by consuming a large quantity of tablets, followed by other tasks including physiotherapy, the use of inhalers and nebulisers, and possibly overnight feeding.

Managing chronic illness can be particularly difficult for adolescents while at school. Secondary schools find it hard to be flexible in accommodating students' healthcare needs and doing so in a way that protects their privacy and dignity. Adolescents and their families feel frustrated when they have to explain their needs repeatedly to new staff or in new situations such as camps and excursions. These problems can be exacerbated when young people need the support of a visiting nursing service. Nursing roster changes may put adolescents in the position of having to explain their treatment needs more than once to an unfamiliar nurse in a school setting that is not designed to provide healthcare. The combined impact of their health support needs and increasing academic demands increases the risk that adolescents with chronic illness will leave school early and not fulfil their vocational potential.

Chronic illnesses adversely affect adolescents in a range of ways. For example, the impact of recurrent asthma symptoms is widespread, with exercise-induced dyspnoea often limiting participation in sport and daily exercise. For those with diabetes,

adolescence is perhaps the most challenging time for illness management: the physiological insulin resistance of puberty is exaggerated in adolescents with diabetes, and the first sub-clinical signs of microvascular complications are starting to appear. Adolescents with cystic fibrosis are more likely to be shorter and thinner than their peers and to have more difficulty with issues of intimacy and sexuality. Although most are socially competent, they tend to take less part in social activities outside the home.<sup>4</sup> Epidemiological studies have shown that adolescents with chronic illness have twice the rate of mental disorders as their healthy peers.<sup>5</sup>

While there is evidence that intensive therapy improves the wellbeing of adolescents with chronic illness, careful organisation of daily activities is necessary to complete all the treatment tasks. This requirement conflicts with adolescents' desire to participate in spontaneous activities being enjoyed by healthy peers and to experiment with new autonomy and freedom from parental control. A major challenge for those responsible for developing new treatment regimens is to achieve a partnership with adolescents to ensure that new programs are both effective and acceptable to the adolescents who will be responsible for implementing them.

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