

Children with chronic conditions

THE AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE, using the definition “a disability which restricts a child’s ability to perform tasks associated with daily living”,¹ reported that in 2002 almost 300 000 Australian children (7.5%) had a disabling chronic illness. The disability was primarily physical in 54% of children, and intellectual/developmental/behavioural in 46%. Asthma comprised 31% of the physical conditions, the rest being other respiratory diseases and diseases of the ears and nervous system.¹ It is estimated that, at any given time, 23% of Australian children have recent asthma, 10% have eczema, and 15% have emotional/behavioural problems. For comparison, 0.5%–1% of the whole population has epilepsy, of which about 60% begins in childhood; about two per 1000 schoolchildren have juvenile-onset diabetes mellitus; and the incidence of childhood cancer is about 14 per 100 000, with a 75% survival rate.¹

Although advances in technology have greatly improved survival for many children (eg, those born prematurely, or those with cancer or cyanotic heart disease), they have also created a population of children living with disabilities. Without belittling these technological achievements, it is important that the quality of life of survivors also be considered. For example, over 50% of extremely low birthweight babies (500–999 g) now survive to discharge, but 15%–20% of survivors have a major disability (cerebral palsy; visual, auditory or intellectual impairment), and at least half the remainder have significant learning difficulties.²

For all children with disabilities, limitations to schooling, mobility and communication constitute the most significant restrictions of daily activity.^{1,3}

Psychosocial impact of chronic conditions. Chronic conditions put increased stress on the child and the child’s parents and siblings. Children with any chronic condition have twice the risk of developing mental health disorders of healthy children, and three times the risk if they have an accompanying disability.³

The clinical “severity” of the condition is not necessarily the major psychosocial prognostic factor. For example, the stress on a family of caring for a child with moderate or severe eczema exceeds the stress related to insulin-dependent diabetes mellitus.⁴ Conditions that disrupt sleep for the child and the parents are possibly the most stressful.

A child’s view of his or her quality of life may differ from the views of parents and others.² Children born with chronic conditions may be more accepting of handicap, even while recognising their difference from other children,⁵ and they often adjust better to visible handicaps than to hidden ones.³ It is important to emphasise what disabled children can do, rather than what they cannot do.

One positive approach to chronic illness is to consider the factors that enable most children and families with chronic illness to cope as well as they do. It has been advocated that

we should focus on interventions to improve this resilience, although there is a dearth of supportive research.³ Robert Louis Stevenson, who had pulmonary tuberculosis, said that “life is not a matter of holding good cards, but of playing a poor hand well”.

The prognosis for a child with chronic illness is highly dependent on how the family functions. The illness places stress on parents and siblings, who may themselves become exhausted and develop psychological problems such as anger and depression. It is vital to communicate well with the parents or carers of chronically ill children, and not to forget the siblings, whose needs are easily neglected if parents focus too much on the sick or disabled child.

Avoidable risk factors for psychosocial problems include prolonged ambiguity about the diagnosis and poor communication to parents and siblings. Other risk factors include stressors such as moving house or changing schools, as well as the known underlying risks of low socioeconomic status, marital discord and parental mental health problems.³

Warning signs of distress in children include problems at school or in social relationships; low self-esteem, manifested as self-blame, helplessness or hopelessness; and denial, including poor compliance with treatment. Psychological problems may manifest as anxiety, depression, oppositional behaviour, suicidality or disorders of eating, conduct or sleep.³

Interventions that have been shown to be beneficial include family therapy, supportive counselling of children and parents, and the use of supportive protocols such as those blending advocacy and liaison work.³ Overall adjustment is better with family-centred interventions and when needs are met in the home.³

Prevention.

Disruptive influences in early infancy can be particularly damaging to later emotional and psychological development. Studies are under way to see if strategies to improve the early childhood environment (eg, parenting support and universal early childhood programs) can effectively optimise development and prevent chronic mental health problems.

Recommendations. Consensus guidelines, developed by an expert panel and based on best available evidence,³ include the following recommendations:

- **Practical support.** Families need clear communication, with healthcare professionals and with each other; opportunities for choice of supports; and practical assistance with



finances, transport, respite care and recreation. Additional support may be needed for staff and peers at school. Many parents report benefits from involvement in self-help groups.

■ *Multidisciplinary teams.* Assessments by well qualified teams can identify areas of immediate and future need and can improve communication between professionals, children and families.

■ *Self-determination.* Young people with chronic conditions should be allowed to decide which professionals coordinate their care, what form of treatment they want, and what part they wish to play in their own treatment.

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