Many children are diagnosed with a chronic illness, requiring complex medical regimens, trips to hospital and possibly invasive treatment. For some, this will place significant constraints on their daily life. What can psychologists do to help them and their families?

What contributes to positive adjustment and healthy outcomes following a diagnosis of chronic illness in a family?

Early three in ten families will have a child who will be diagnosed with a chronic illness (defined as a condition lasting longer than three months: U.S. National Center for Health Statistics). This is the beginning of a long and challenging journey. It will involve regular visits to hospital, a need to ‘adhere’ to complex medical regimens and demand changes in what should be eaten and what can be done. Immediate and ongoing medical investigations may be invasive, uncomfortable or painful, with treatment regimens requiring medication, injections, blood measurements, brain or body scans. One in ten children will have a chronic illness that is severe enough to substantially limit their daily life and demand extended care and supervision (Yeo & Sawyer, 2005).

Grasping the immediate and long-term implications of diagnosis is a complex process for the child or young person, parents and the wider family. Taking in the immediate demands of treatment can be confusing and frustrating. The realisation of the potential long-term impact of the illness on a young person’s hopes, dreams and ambitions can be devastating.

A positive adjustment to chronic illness can be thought of in normative developmental terms as the maintenance of positive emotional well-being, age-appropriate behaviour and developmentally appropriate self-esteem/self-worth at the same time as accurately following complex medical regimens. Coping with an event (like a diagnosis) ‘well’ involves implementing strategies that involve assessing what we think about the event and then considering what we do about it. Lazarus and Folkman (1984) suggested people initially appraise whether a life event is harmful, beneficial or benign. This is followed by a secondary appraisal which considers whether the threat can be overcome to either minimise the negative consequences or optimise adaptation. How children, young people and families appraise this threat will influence their ability to cope with the situation (Folkman, 1999).

Chronic illness has a substantial impact on emotional life, lifestyle, education, self-esteem and social relationships as well as physical well-being (Yeo & Sawyer, 2005). The illness/condition can pursue a relentless process resulting in isolation from peers and family. This can hinder the development and maintenance of friendships and with increasing dependence on parents. Adolescent chronic illness can both prevent the development of independence as well as impact on that which has already been achieved (Christie & Viner, 2009). Young people with chronic illness report a lower quality of life compared to healthy peers and also a disruption in their family structure (Melesi, 2002). Twice as many young people with chronic illness have high levels of depression and anxiety in comparison to healthy peers (Cadman et al., 1987).

**Beginning the journey**

Initially families go through a period of limbo, beginning with uncertainty and worry and then slowly moving into a ‘new normal’ by reconstructing their world. Families reorganise roles, assign meaning to the illness and may go from a long-term to a short-term ‘one day at a time’ focus, establishing new daily routines (Clarke-Stefan, 1997).

Parents and young people are often angry at the initial diagnosis. They can be angry with each other for ‘causing the illness’ by passing on ‘bad genes’ or not having gone to the doctor early enough.
Children can often be angry at parents for not having protected them. One little boy told the team ‘Mummy gave me diabetes’ when she had taken him to the hospital. Grief is also reported in relation to loss of how life used to be, as well as loss of a future, which may now include long-term impairment, disability or early death. A loss of spontaneity with restrictions on activities may also create a sense that things will never be the same again (Gannoni & Shute, 2010).

When families start to build a new world that incorporates the illness, they make physical and emotional adaptations and constantly revise their assumptions of the world. Lowes et al. (2005) found that for families living with diabetes, the longer the time after diagnosis the better the adjustment to ‘normal’ life. However, the parents were clear that they never fully ‘accept’ the diagnosis. Although they adjust to the management of the diabetes, they still described episodes of grief seven years post-diagnosis. The reaction is triggered by changes in regimen, injections, hospitalisation, discussions about diabetes control, worry about complications, attending clinics and meeting new medical teams – anything that reminded them that their child is different (Bowes et al., 2008).

The amount of stress reported by children and families is related to various factors: the adherence to the medical regimen; the frequency of hospital visits; and even gender, with parents of boys with bladder extrophy having more difficulty with catheterisation than parents of females (Mednick et al., 2009). For children with diabetes, difficult injections and blood testing can influence metabolic control, adjustment, quality of life and well being (Malik & Koot, 2009).

**The risk-resistance adaptation model**

Wallander proposed a risk-resistance-adaptation model that determines a child’s physical, neurocognitive and psychosocial adaptation (Wallander et al., 1989). When risk factors (disease/disability, functional independence, psychosocial stressors) are excessive, and resistance factors (intraperonal, socio-ecological, stress processing/coping strategies) are low, there are difficulties in emotional, physical and psychosocial function and adaptation (Brown et al., 1993).

**Risk factors**

Disease/disability parameters include the diagnosis, disease duration, severity, acute and long-term complications, visibility, impact on brain function and cognitive functioning. Many chronic conditions can have lasting cognitive effects. Children with sickle-cell have been found to have small deficits in cognitive function (Schatz et al., 2002). Children with diabetes are particularly vulnerable to reduced processing speed, impaired memory difficulties (Hershey et al., 2000), attention (Rovet & Alvarez, 1997) and reductions in verbal intelligence (Northam et al., 1998). Epilepsy can also have a range effects, dependent on the type of anti-epileptic treatment (Lagae, 2006). Children with epilepsy are susceptible to learning difficulties (Fastenau et al., 2008) and a deficit in working memory and processing speed (Whigham & Burns, 2008). Research shows child cancer survivors to have lower IQ with varying cognitive effects dependent on age of diagnosis, type of treatment and length of disease (Christie et al., 1994).

Functional independence is related to the impact of the chronic illness on activities of daily living, including personal care, mobility and communication. The impact can vary across the course of a chronic illness as well as having disease-specific effects.

School can be a significant challenge with physical symptoms and multiple hospital appointments impacting on attendance, performance, motivation and attitude towards school, as well as the child missing out on recreational and sporting activities (Neo & Sawyer, 2005). Children struggle to catch up on work, which impacts on exam results and future career choice. Young people interviewed about the impact of a chronic
illness on school describe how missing school can cause relationship problems, such as difficulty in re-initiating friendships on return to school as well as struggling to handle questions about their absence and illness (Gannoni & Shute, 2010).

Psychosocial stressors include daily hassles, negative life events, perceived stress, maternal depression/distress and neighbourhood disadvantage. Disease-related daily hassles may include medical appointments, daily injections, having to be home-schooled, special dietary requirements and/or parents giving up full-time work to care for their chronically ill child. Disease-related daily hassles have been found to be a risk factor for emotional distress and poor adjustment in mothers. Parents report poorer marital satisfaction, with mothers at greater risk of negative mood (Cadman et al., 1991).

Resistance factors

Intrapersonal factors are a key component of the risk-resistance model. Family cohesion is key mediator of childhood temperament, personality and emotionality, as well as competence, self-motivation and problem-solving skills. Positive impact on adjustment is influenced by the level of family support children and parents receive, as well as the affection and nurturing given to the chronically ill child.

Socio-ecological factors have been found to play a significant role in helping children and parents adjust to chronic illness. Low levels of family conflict, good family relations and support, marital satisfaction and a social support network lead to good adjustment (Cadman et al., 1991). Family cohesion, parenting satisfaction, socio-economic resources, maternal employment, social support and parental education are all related to positive psychological adjustment in children with asthma and diabetes (Hamlett et al., 1992), spina bifida (Vermaes et al., 2005), sickle-cell (Brown et al., 2000), juvenile rheumatoid arthritis (Helgeson et al., 2003), juvenile chronic arthritis (Huygen et al., 2000) and Hirschsprung’s disease (Athanasakos et al., 2006). Solday et al. (2000) reported that irrespective of whether a child was chronically ill or not, families with higher cohesion and expressiveness and less conflict had less parental stress.

Stress processing involves cognitive appraisal and coping strategies. Families use a range of different strategies to cope at different times in the course of the illness. Planful problem solving is seen as one of the most adaptive strategies. Problem solving supports positive reappraisal, which involves taking positive steps when thinking about the impact of the illness. Positive reappraisal can help replace anger and sadness with satisfaction and pride. Engaging and searching for help and advice and social support are other positive and adaptive coping strategies used by families (Azar & Solomon, 2001).

Parental stress is also reduced by having information regarding their child’s chronic illness and having the opportunity to speak to other parents in a similar situation (Hartman et al., 1992). Access to information has been significantly improved by the development of the internet, although access to information has been significantly improved by the development of the internet, although families may often need help negotiating the good, the bad and the ugly that increasingly exists in the ‘cloud’.

Emotion-focused coping involves addressing future concerns, using psychosocial interventions and thinking about the meaning of the condition. Folkman and Moskowitz (2000) wrote about ‘attributing special meaning to ordinary events’. This is where under stressful conditions individuals may fuse ordinary events with positive meaning. When a negative event occurs, the individual creates a positive event or interprets an otherwise ordinary event as positive as a way of offsetting the unpleasant affective consequences of the negative event.

Parental relationships and family life both affect and are affected by chronic illness. Parents worry over the long-term, uncertainty about the future, medical procedures and finance. Parents often have to take time off work to attend appointments. Loss of pay and costs of travelling to hospital appointments can create additional stress in the family system (Gannoni & Shute, 2010). For some parents the balance between maintaining an enjoyable career and managing the complexities and demands of a treatment regimen becomes untenable.

There is more assumption than...
evidence in relation to differences in how mothers and fathers cope; however, it is suggested that planful problem solving is used more by mothers (Azar & Solomon, 2001). Mothers tend to take a primary role in supporting adherence to the medical regimen, attending clinic visits and providing practical and emotional support. Mothers also use more coping strategies than fathers, particularly when the ill child is a girl.

Paradoxically, when mothers were felt to be too controlling, particularly with girls, this increases the probability of depression in the young person (Berg et al., 2007). It has also been reported that how parents perceive the impact of the illness influences adjustment, with mothers who had extreme attitudes of overprotection with children with diabetes reporting poor adjustment (Swift et al., 1967).

For mothers of children with asthma, Rydstrom et al. (2004) found a greater impact on family life than in families living with diabetes. Parents reported that the disease leads to uncertainty and a need for mothers to always be available for the sick child. This means they were seen as less available for partners or siblings, who described this as 'distancing', which is found to be symmetrical coping strategies, with both mothers and fathers feeling that each are uninvolved there is parental involvement children are excluded and describe missing out on special event days (Gannoni & Shute, 2014). However, negative appraisal of the impact of the condition on their physical health, low maternal worry and promote child self-worth or self-esteem (Immelt, 2006).

**Conclusion**

The impact of a diagnosis of a chronic illness on families, children and young people, and the adjustments that they make in order to overcome future challenges, are dependent on many interrelated factors. These factors are both internally and externally determined and the role each factor plays in enabling positive adjustment is complex. Many young people draw upon a range of strengths and abilities, and parents and families can act as significant resources.

Psychologists working in paediatric and adolescent medicine services have the specialist skills to understand the complex relationship between physical and emotional well-being. However, all healthcare professionals have the opportunity to help families identify strengths, abilities and resources in order to contribute to positive adjustment and healthy outcomes. Healthcare professionals can also make a significant contribution to positive adjustment by ensuring they offer, timely, thoughtful, effective and accurate information, communicated at the time of diagnosis but also reviewed and repeated at different developmental stages. Ensuring successful adjustment is the responsibility of everyone in the young person’s support network.