



Child with chronic illness

Six-week old Meg has just been diagnosed with cystic fibrosis, Johnny (who is eight) has a heart condition, and ten-year-old David has undergone repeated surgery to correct the effects of neurofibromatosis on his spine.

Parents grappling with these, or other chronic medical situations, are facing something that fundamentally feels 'wrong' – a child facing illness, painful medical procedures, and daily medical and physical management routines. Stressors arising from these circumstances are far-reaching for the children themselves, their families and their wider networks. Chronic illness has effects that impact on a number of areas of functioning – the biological, psychological, and social/environmental areas. In return, the strengths and weaknesses that were present in these areas before the illness occurred have an impact on the illness itself. Thus, the pre-existing physical and psychological resources of the individual family members and their supports in the wider community, together with the nature of the illness itself, determine the family's adaptation to the illness.

Chronic illness has been described by some as "having a personality and functioning like another family member". In a way, the illness takes its place within the family as another member, making demands of the system and bringing about changes (negative and positive). There are distinct phases in the life cycle of any illness. These phases pose their own demands and task requirements for the family. First, a crisis phase may include symptomatic periods before a diagnosis is made, periods of hospitalisation, and the initial period of readjustment after diagnosis and initial treatment. Normal emotional reactions may include shock, anxiety, anger, sadness and confusion. After adjustment has occurred, it appears as though everything is slightly changed. Nothing will ever be quite the same again and there is grief for what is lost and dreams that must be given up. Second, the chronic phase may be constant or relapsing, where periods of stability are interspersed with periods of upheaval or exacerbation. For long periods, life may be settled and calm and the family may carry out normal routines. However, the spectre of a crisis always hangs over their heads.

Progressive illnesses (in which the child's condition can only deteriorate) require a specific type of family adaptability. Such illnesses may require less ongoing active care-taking or role change, but the episodic nature requires a flexibility that permits the family to move between two forms of family organization – one focused on crisis management, and the other focused on the day-to-day demands of living. The ability of the child and family to manage a semblance of normal life alongside everything else that is happening is a key task and will determine healthy adaptation. Continuing on with routines, rituals and celebrations provides an important sense of normality and belonging. An example of this could be a ritual a family has of having treats, a game or a video on a Friday night, which can still happen in hospital or in the child's bedroom.

Psychological factors that impact on the family's adjustment include the beliefs held by the child about the illness and its impacts. The developmental stage and cognitive style of the child will also influence the beliefs they hold. For example, younger children hold more magical and egocentric views of illness ("I'm sick because I wasn't good"). By the age of

ten, a child may have a reasonably accurate, though not adult, understanding of the illness and its implications. At this stage, the child will be becoming more aware of how the illness sets them apart from peers and, that in some cases, that the illness will not go away.

The older child may be expected to accept some responsibility for illness management. This stage is frequently met with denial and refusal to accept limitations imposed by the illness. Poor compliance with treatments may occur in the child's attempt to be like everyone else. These reactions are not necessarily specific to age and may occur at any point in the lifespan, especially at points where new adjustments are called for. Denial and non-compliance can also occur when a new development in the illness calls for a more intensive, invasive or demanding approach in treatment which may perhaps be more obvious to peers in a school environment. Associated stresses may include bullying or rejection by others and reduced participation in sport or other activities. The child's beliefs will be influenced by the parents' own beliefs about the illness and how illness was reacted to in their own childhood. A parent who comes from a family where complaints of ill health were discouraged and little sympathy was provided, may find a nurturing role somewhat uncomfortable.

A child's temperament will also affect adaptation to the illness. An easy, adaptable, go-with-the-flow temperament is likely to assist the child in their dealing with challenges. Intelligence, healthy sense of self as separate from the illness, a sense of humour, and healthy attachment with carers will enhance adaptation. The child needs to see the parent coping and presenting the attitude that, "no matter what happens, we are OK and we can deal with it". For the parent, coping with negative emotions appropriately and accepting adult support are crucial.

Social factors of importance in coping include age-appropriate and flexible boundaries for behaviour, clear family role functioning, available support, regular and clear communication and conflict resolution. In parents' attempts to care for and nurture their child they may adopt a protective mode which may make it more difficult for the child to negotiate some of the normal developmental tasks of separation and individuation from the family. Another potential difficulty lies in the sphere of behaviour management. In a parent's attempt to reduce further stress on a sick child they may shy away from firm approaches to the management of difficult behaviour. This can inadvertently reinforce, and push up the frequency of, the undesirable behaviour. Clear, consistent management can provide a framework enhancing security and limiting anxiety.

A family's ability to achieve a balance between protecting their own identity while remaining open to healthy outside influences maximises the child's potential for healthy adaptation. A family isolated or closed off from outside influences provides a fertile ground for dysfunctional patterns to develop. On the other hand, a family with no identity of its own as a family and with no boundary to outside influence, provides little connection or sense of belonging to its members.

While chronic illness clearly brings numerous stresses to a family's life, it is obviously not the only source of stress. These other stresses may range from daily hassles right through to major trauma. Common sense would suggest that the greater the level of accumulated stress the family is exposed to, the higher the risk of adjustment difficulties. While severe psychiatric difficulties are not common there is a risk of mood and anxiety

problems in both parents and children and when these persist and interfere with functioning they will require treatment in their own right.

While chronic illness is associated with much loss, adjustment and difficulty in a family, there are also positive aspects. These include a greater awareness of the priority of family and relationships and the value of communication and quality time. Very strong bonds are formed both within and outside the family and a heightened sense of what is really important in life may foster prosocial values in all those involved.

