

As many of you will know, unfortunately there are several cases of arachnoiditis in children. It is not really feasible to cover in great depth the psychological ramifications in an article of this type, but I do feel that a brief mention of some aspects may be helpful.

About 20-25% of children in the United States have a chronic health condition, and the number of children with activity-limiting chronic conditions has tripled since 1960.

In Northeast Ohio, for example, more than 25% of all children's hospital admissions are for chronic conditions.

A study in Massachusetts in 2000( [\[1\]](#) ) found that long-term needs may not be met adequately and in particular, the need for information was often not met. In fact, some 91% of the parents surveyed in this study reported that they would like to obtain more information about the child's condition, treatment and +long-term implications.

A number of resources suggest that chronically ill children are at risk of inadequate health care delivery and that facilities are often poorly co-ordinated.

Poor healthcare can equate to increased school absences and hence school failure as well as reduced socialisation.

Children with chronic illness may require burdensome daily treatment regimens as well as frequent medical consultations including repeated hospitalisation. This can impact severely upon education and socialisation as well as contributing to family disruption.

However, many of these problems may be mitigated or avoided by appropriate medical and

social facilities and care, with particular attention to home-based care.

Many studies have looked at children's needs via the interpretation of their parents, most often the mother. Drawing useful conclusions from these, however, is reliant upon the accuracy of these interpretations.

Often chronically ill children are not visibly affected but they suffer from what is termed 'high morbidity', which means that they are affected in a number of ways and these can be quite severe. As one Paediatric website puts it: very simply:

"The needs of children with chronic medical conditions are great."

A recent study in Tennessee ( [\[2\]](#) ) found that children with chronic illnesses often adapt to their conditions by repressing their emotions, although they are not just in denial, but genuinely regard themselves as well adjusted, self controlled and content, tending to organize their behaviour to protect that self-image.

The children may score low for depression and anxiety but tend to rate high for defensiveness: a tendency to avoid or deny negative thoughts about oneself.

However, the question as to whether this defensiveness is helpful or a hindrance remains unanswered.

It may be that by blocking out depression and anxiety, defensiveness may help children better deal with practical demands of their illness; on the other hand, repression of these feelings might also result in children ignoring important signs of disease progression.

SUPPORT ORGANISATIONS can be of great help.

For instance, the American-based Starbright Foundation ( <http://www.starbright.org/> ) has set up

a project called Starbright World, which involves ill children in a virtual world through which they can communicate with each other across the States.

Steven Spielberg is Chairman of the Foundation; as regards the project, he says:

"Maybe it's just for an hour during the day. But for that hour they can escape from their pain and their reality to a place where anything can happen."

The Foundation also publishes videos designed to help children with chronic illness. Videos are free to parents and children in the US, (I'm not sure about UK) and can be ordered from: <http://www.starbright.org/projects/vwa/index.html>

. Or:

The Starbright Foundation

11835 West Olympic Blvd., Suite 500  
Los Angeles, CA 90064  
Phone: (310) 479-1212  
Fax: (310) 479-1235

### **Suggested reading:**

Coping With Your Childs Chronic Illness by [Alesia T. Singer](#) , [Alesia T. Barrett Singer](#)

[Easy for You to Say: Q & A for Teens Living With Chronic Illness or Disability](#) by Miriam Kaufman

[\[1\]](#) Perrin EC, Lewkowicz C, Young MH *Pediatrics* 2000 Jan. 105 (1): 277-285 *Shared Vision: Concordance Among Fathers, Mothers, and Pediatricians About Unmet Needs of Children With Chronic Health Conditions.*

[\[2\]](#) [Phipps S, Steele R.](#) *Psychosom Med.* 2002 Jan-Feb; 64(1): 34-42. *Repressive adaptive style in children with chronic illness.*