

## Living with a Pectus Deformity

Even with severe deformities, the heart and lungs have normal growth and development. However it is documented that pectus deformities affect heart and lung function (Haller and Loughlin, 2000, Fonkalsord and Bustorff-Silva, 1999).

In pectus excavatum, it is believed that the heart is displaced to the left side of the chest, and there is a restriction of movement of the heart and lungs. Patients complain of a decrease in stamina and endurance during strenuous exercise (67%), frequent respiratory infections (32%), chest pain (8%) and asthma (7%) (Fonkalsord EW et al, 2000).

However recognition of these symptoms remains controversial amongst physicians as the evidence that exists does not reliably and consistently demonstrate physiological limitations. Whilst the physiological effects of pectus deformities remains debatable, the psychological difficulties facing patients are evident and yet there is sparse published information regarding these.

Some patients are able to accept and live happily with the shape of their chest; this is an important point as health care professionals frequently assume a person with a physical disfigurement has a negative image of himself (Anderson, 1982). However many patients with pectus deformities are affected with a negative self-image and low self-confidence. 'An unwillingness to be seen without a shirt while swimming and participating in sports or social activities,' is the most frequently quoted complaint. In fact living with a pectus deformity affects all areas of life (Table 1).

**Table 1:** Reactions of patients 11 years and over with funnel chest (Einsiedel & Clausner, 1999)

|                                 |     |
|---------------------------------|-----|
| High degree of self-observation | 94% |
| High latent anxiety             | 82% |
| Broken motivation               | 82% |
| Feelings of stigmatisation      | 78% |
| Timidity on social contact      | 74% |
| Disturbed body image            | 72% |
| Ambivalence                     | 72% |
| High latent aggressiveness      | 66% |
| Inhibitions                     | 66% |

As patients become older their psychological problems increase (Table 2)

**Table 2:** Reactions in patients aged 18-35 with funnel chest (Einsiedal & Clausner, 1999)

Excessive and over extensive dependence on parental home  
Alcohol and drug abuse  
Absence from work

Suicidal tendencies  
Psychosomatic symptom displacement  
Generalised hypochondria

Several factors make the problems patients with pectus deformities face and the way in which they cope with them unique.

- **Age**  
Progressive growth spurts lead to a marked deformity by adolescence. Wright (1960, as cited by Anderson, 1982) identifies adolescence as being the most difficult age for incurring a disfigurement. The importance of peer acceptance, conformity to adolescent norms, interdependence from family ties and an exaggerated perception of physique can be problematic. Schilder (1935) describes body image as 'the picture of our body which we form in our mind, that is to say the way in which our body appears to ourselves'. Schilder also states that body image is dynamic, that is, it changes during the life cycle. During the teenage years the patient may be acutely aware of the shape of their chest, however once they have career, family, financial commitments, their attention may not be so focused on their deformity.
  - **Body area**  
Society, and the media in particular, places a high value on physical appearance and physique, especially in teenagers. Many adolescents with pectus deformity feel unable to expose their chests by wearing low cut or open tops and often disguise their deformity by wearing loose fitting clothes. Schilder (1935) confirms that short-term alterations such as changes of clothing can alter body image. Acceptance of a disability or disfigurement is easier if the affected part of the body is not central to a person's self-concept, i.e. if a person valued intelligence, personality or relationships rather than physical beauty they would be more likely to adapt to the disability (Anderson, 1982).
  - **Attitudes of others**  
Interpersonal relationships and attitudes of others also affects a person's self-concept. People, particularly adolescents, not only search for their identity from within but also from others (Anderson, 1982). In turn, other people use cues individuals give them, to help them define themselves. The relationship with and attitude of persons closest to the person with disability have particular significance. Parental attitudes toward disability seem to be a particularly important determiner for a child's adjustment to disability (Pringle 1964, as cited by Anderson, 1982). Some parents dismiss the pectus deformity as being part of the person, for example colour of hair or eyes. However other parents do seem to draw attention to the deformity and heighten anxiety. The parents of young children can affect how well their children cope with their deformity and may allow avoidance of major surgery later in life.
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