



THE IMPORTANCE OF GOOD MANAGEMENT

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Children with chronic constipation and soiling present with complex management issues involving both physical and psychological factors. Effective management is necessarily integrated and may involve a team of specialists. A paediatrician, surgeon, continence nurses and physiotherapists all have expertise in managing these children using a multi-disciplinary approach. Management needs to involve families, carers and often school or kindergarten staff in addition to sensitive and effective communication with the individual patient. Those children who have already had several years of unremitting symptoms despite treatment with laxatives and behavioural programmes present even greater challenges. Most children diagnosed with slow transit constipation are in this situation.

Early recognition and prevention should be the aim of everyone in contact with children who soil. The management of all the related issues begins with ensuring there is empathetic and clear communication between all the people involved; the child, their family and carers, their teachers, their extended family and friends. Maintenance of privacy and discretion for the child is important. In school, for example, having systems set in place for ease of access to bathrooms and assistance as necessary without drawing attention to the soiling can transform a child's experience.

If peer relationships have become very difficult a chance to 'start afresh' with peers in a club or hobby group may be helpful. Care needs to be taken in selecting the group and ensuring that there is sufficient communication with the adults involved to avoid any misunderstandings.

Family support is extremely important and parent run groups such as Nidkids Support Group or the Paediatric Continence Association of Australia Inc are invaluable. These organisations provide a network so that families feel less alone. They can offer families a variety of practical solutions to problems based on personal experiences. Families can learn from others who are well adjusted to these issues and this can help to lessen the stigma associated with the problems. Counselling and psychiatric services can often be an important additional treatment. Good communication between medical advisors and counsellors is likely to increase the success rate of any treatment.

The child

The child's distress can take many forms. Children may feel anxious and may feel sad and depressed or angry about their problems. Children may become obviously tearful and withdrawn; they can also 'act out' aggressively as a reflection of their feelings. This anger may present as oppositional behaviour, directed generally or specifically around the treatment (washouts, etc) or as aggressive outbursts towards siblings, parents or friends. Soiling is embarrassing and usually occurs in much younger children who are not yet toilet trained. This can magnify a child's feelings of inadequacy and poor self esteem. This late development of "independence" may also affect relationships between parent and the child; encouraging very close and potentially 'enmeshed' relationships. New friendships may become more difficult to form and previously close family members may feel excluded. Sometimes a child may even subconsciously use their symptoms to maintain this dependency. The child needs to understand very clearly that the symptoms are not their fault. They need to be reassured and reminded about their many skills in other areas to help diminish their negative thoughts about themselves. It is also important that they do not harbour any false beliefs about why they have their medical condition. It is not uncommon for children with a chronic illness to feel they are being punished for something. Such beliefs must be identified and carefully corrected.

The Parent

Parents experience considerable stress associated with having a child affected by STC; seeing their children unwell and not being able to solve the problem. Repeatedly trying to persuade an unwilling child to have treatment can take its toll. Parental grief over loss of the 'normal child' can also be an issue for families. The added pressure of a chronically ill child can precipitate marriage/relationship difficulties. The child's adjustment to their problem will be more difficult if their parents are not coping well. They will be worse if the parent is fearful or over-protective, guilty, embarrassed or shamed. Parents who had pre-existing anxieties or other health problems are at risk of developing these less adaptive responses.

Siblings

Brothers and sisters may feel excluded, isolated, deprived and resentful of the affected child who needs so much of their parents' time. They may become distressed by their sibling's discomfort and treatment regimes. Marked sibling rivalry and attention seeking behaviours can occur in young siblings. Older children may look outside the family for support and attention, resort to risk taking behaviours or develop significant emotional problems of their own. It is important to include siblings in treatments and visits. If they are not involved they will often worry more. By increasing their understanding of the problem they will cope better with the disruption it causes to the family unit. Sometimes a family meeting together to discuss problems openly will be beneficial. Family therapy with a counsellor can be very helpful in re-establishing more effective communication and patterns of behaviour within families.

Grandparents and extended family

Grandparents, extended family and friends may be very confused and puzzled that an affected child takes up so much of the families' time. Family members may give advice that is not helpful and sometimes can undermine treatments if they are not involved in discussions explaining the nature of the problem. In some families tensions can mount if family members infer poor management by the parents has led to difficulties. Everyone has their own beliefs about constipation and usually there are plenty of old wives' tales about the dangers of laxatives! In some families grandparents become very involved in the family, taking care of siblings, supporting the family because of the illness of the child. This can put undue pressure on them and is sometimes a concern as they get older. This may increase the burden of guilt on parents and further strain relations. Grandparents and extended family may feel guilty that they have passed on 'bad genes' that have caused STC. They may feel very helpless when they see what their child's family is going through with an affected grandchild in the family.

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