



Invisible Illness

—an online resource about children and young people with chronic conditions for school communities



Slow Transit Constipation (STC)

Organisations who wrote / approved the information

Paediatric Continence Association of Australia (PCAA)

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***Chronic Illness Alliance
www.chronicillness.org.au
03 9882 4654***

Slow Transit Constipation (STC)

A: FACTS ON THE CONDITION

1. General description, including different types, causes, prevalence, signs and symptoms

Chronic constipation is a major problem in the general community, but is not commonly discussed and its prevalence is underestimated. Common constipation is when a child has hard faeces (stool) or does not go regularly. There is a lot of difference in the firmness and frequency of stool in normal children. Constipation is quite a common problem in children, but with improvement in bowel habits and appropriate use of medications, it can usually be controlled.

However, there is a subgroup of children that present with slow transit constipation (STC), that have a functional abnormality because of disordered nerves and muscles of the colon itself. Many children with STC have been found by biopsy to have abnormalities of the neurotransmitters (messenger molecules in the nerves) in the muscular layers of the bowel wall. In particular, they have a deficiency of Substance P, a peptide thought to be involved in the activation of bowel contraction. In these children, movement of stool within the colon is markedly delayed. In kids with STC the stool often remains stored in the right or middle portion of the colon and does not progress adequately to the rectosigmoid colon, causing a build up and discomfort. It is the rectosigmoid colon that is responsible for the propulsion and transfer of stool (poo) out of the body.

The symptoms of STC include long delays in the passage of stool, accompanied by lack of urgency to move the bowels. It has been determined that the normal frequency of stool passage is three or more bowel movements per week, however in children with STC often they do not pass a stool for 7-10 days at a time; at times longer. Physically, many children with STC do not appear unwell. Sometimes this can lead to inaccurate perception that their health problems are not significant. These children and their families can face considerable difficulties, with distressing symptoms and never-ending treatments.

Many children who have been diagnosed with STC (and some other children with difficult to manage constipation and soiling) continue to have symptoms even with the best treatment available at present. They may have nausea, abdominal pain, poor appetite and soiling. They often have had symptoms for some time and many frustrations associated with their poor response to treatments. They may have had unpleasant treatment regimes. The management may have involved uncomfortable and potentially frightening procedures, including repeated enemas. Treatments will often have included large doses of laxatives orally or by naso-gastric tube and many children will have had multiple hospital admissions for these treatments.

Despite the best efforts of health care providers and families, these children may feel different, depressed, angry and sometimes isolated and rejected. Their self esteem is often low. Some children have abdominal surgery, which can improve their physical symptoms but may exacerbate their feelings of difference. Children and young people need time to adjust to stomas or appliances and often feel self-conscious about their surgical incisions or scars. The incidence of behavioural and emotional problems in studies of children with constipation/soiling is high.

There is no need for a routine abdominal X-ray to diagnose constipation. A potentially more helpful test is a transit study. This can be done with radio opaque markers and standard X-ray or in nuclear medicine with a radio labelled drink. The test measures movement of faeces through the bowel. It can distinguish general colonic slowness (STC) from functional faecal retention in the rectum only.

Prevalence

Research reveals to date that one in 3000 infants and adults, of any gender, are diagnosed with STC. The condition has a genetic predisposition.

Signs and Symptoms

STC can affect young infants from birth, resulting in delay of the first stool (black meconium). Symptoms include constipation, nausea, bloating of the stomach, lack of appetite, bad breath and abnormal sleeping patterns. The child can develop faecal soiling which can interfere with parenting and infants' welfare. Pressure from the full bowel can also cause incontinence of the bladder, often causing a confusing initial diagnosis of the condition.

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2. Treatments, including role of specialists, effects of treatments, use of devices, daily routines

STC is a chronic condition for which there is currently no cure. Patients diagnosed with this condition may undergo various treatments to assist in making their lives more comfortable. Laxatives may offer temporary relief for some of the children; however their effectiveness can be limited. Dietary manipulation is usually ineffective. High fibre may contribute to a worsening of symptoms for these children. Other treatments include nasogastric washouts, high doses of laxatives, and enemas. Surgery may be offered when standard medical therapies have failed.

Chait Button

An appendicostomy (stoma) is a small opening in the abdomen wall, which leads to the caecum (large bowel). A tube is usually inserted through the appendicostomy (Chait button) with a small port which is covered by a cap. The child's colon can then be directly accessed for bowel washouts two to three times a week. This form of treatment allows families to give the washouts at home, reducing stress and keeping hospital visits to a minimum.

Interferential Therapy

Interferential therapy is painless electrical stimulation performed by a physiotherapist. It stimulates the nerve supply of the bowel, and may assist in the reduction of constipation and incontinence. This treatment is typically performed three times per week for a four-week period.

B: THE CONDITION'S EFFECT ON THE CHILD/YOUNG PERSON

1. Effects on the individual

Children with chronic constipation and soiling present with complex management issues involving both physical and psychological factors. Young people with a diagnosis of Slow Transit Constipation (STC) present even greater challenges. STC is a recently discovered condition where children are born with a neuronal abnormality/s of their colon which impacts on the peristalsis of stool (poo) passing through the colon. Effective management is necessarily integrated and may involve a paediatrician, surgeon, continence nurse, physiotherapist and parent educator; all having expertise in managing these children. Management needs to involve families, carers and often school or kindergarten staff in addition to sensitive and effective communication with the individual child. Those children who have already had several years of unremitting symptoms despite treatment with laxatives and behavioural programs present even greater challenges. Most children diagnosed with STC are in this situation.

Early recognition and prevention should be the aim of everyone in contact with children who soil, in particular a young person with STC. 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. Counselling and psychological 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.

Generally, children with this condition may live a very active life despite their intrusive treatment regime. These children can often adjust to the illness and participate in the same activities as other children. Sporting activities are recommended although children with stomas or pouches need protection to prevent injury to the stoma site.

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2. Effects on those close to the child/young person

Once diagnosis is obtained, parents can experience high levels of stress and anxiety. Not having a cure for the illness and watching the child suffer in pain often takes its toll. Stress also occurs when a child is not compliant with treatment due to their frustration with their illness. The added pressure of a chronically ill child can precipitate marriage/relationship difficulties.

Parents and siblings can feel a strong sense of hopelessness when treatment is unsuccessful. This often leaves families, friends and carers with feelings of frustration and depression. Siblings may feel excluded, isolated, deprived and resentful of the ill child who needs so much of their parents' time.

3. "In Their Shoes" - stories from children/young people with the condition

Story One:

Thomas had seen doctors many times in the past and was treated with laxatives and frequent enemas. He found the treatment frightening, painful and difficult. He did not understand the nature of his bowel difficulties. He did not like taking about it.

He did his best to disguise his symptoms even from his family. Thomas hid his smelly soiled underwear in the back of his drawer, or under his bed ignoring the soiling. He spent a weekend away with friends and despite being in considerable pain and distress he did not let on about his problem but had to fob off endless question about why he was spending so much time in the bathroom. He had not told anyone there about his constipation and soiling.

His mother only became aware that his symptoms had worsened when eventually his soiling became so frequent he could no longer hide the evidence. Thomas then began receiving appropriate treatment and most importantly came to understand his condition better. He said at this time he had not told anyone initially because he did not want to have to go back to the doctors and be talked about and that he was afraid of the treatment especially the enemas. Discussing the nature of his bowel disorder in a way he could understand and involving him in the choice of treatments led to a much better outcome.

Story Two - Anita, 12:

"I've missed heaps of school. Last year I was in hospital twenty times and each time for five or six days. I don't really like school because I'm not very good at things, probably because I've missed so much, but I want to get there so I can learn. Some of the kids freak when they know I have a disease. They don't want to come near me because they think they'll catch something. They often call me names. One boy threw his cap in the bin because I'd touched it. He even told me he hoped I'd die from my disease. We're doing a debate at school at the moment about whether or not products should be tested on animals. One of the boys said they shouldn't test stuff on animals, they should test it on me instead. I get upset when people say things like that, but I try to laugh or ignore them. This kid asked me one day, 'Are you going to die?' I just said, 'No' and walked away."

Story Two is an extract and is reproduced with permission from:

*Cameron, Heather (ed.), "Different but the same. Young people talk about living with serious illness."
Lothian, Port Melbourne, 1998*

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C: STRATEGIES FOR SCHOOLS/TEACHERS

1. Overview of strategies for schools.

When the children go to school, soiling and the associated smell, can lead to isolation and they may be ostracised by their peers. Name-calling and exclusion are frequent and children can feel despair and defeat as a consequence. School refusal by the child may be the first hint of these issues. The teachers' attitude is very powerful in shaping that of other students particularly in the early primary years. Teachers are well placed to assist the child in establishing friendships and status amongst their peers.

The school may need to provide practical support. There may be a need for facilities such as easy access to a private toilet, lockers for spare clothes and shower. There may also be a need for assistance from a staff member with a child soils.

School attendance can be further reduced by symptoms, the need for hospitalisation and appointments. This can act to reduce friendships and peer involvement even more. To minimise this children should be encouraged to participate fully in school life including camps, excursions and sporting activities.

Some children may miss considerable schooling or be regularly unwell at school so it is important that they have access to the services available for children with chronic illnesses or disabilities if this is appropriate.

2. Link(s) to useful other online resources for schools on strategies in responding to a child/young person with this condition

Further information can be found at the PCAA website www.pcaa.org.au

D: FURTHER INFORMATION

1. Organisations, including services and resources available

In 2004 Paediatric Continence Association of Australia (PCAA) was formed to provide information, education and support to families with children with all forms of bowel and bladder dysfunction. PCAA is a registered health promotion charity with ITEC and DGR tax status. The formerly known Nidkids group became an auspiced program under the PCAA to support kids with NID.

PCAA services include:

- Over 15 volunteer staff (including qualified community development, disability, social work, counselling and nursing practitioners)
- National office based in Chirnside Park
- 3 national conferences held at RCH for the medical, allied health and community sectors
- Formation of Paediatric Continence Advisory Council (medical, allied health, education & community sector representation)
- Parent education fact sheet series (24) and educational management booklets for Anorectal anomalies and STC
- Twice yearly (summer & winter) camps for kids with bowel and bladder dysfunction
- Telephone counselling and extensive website www.pcaa.org.au
- Parent education sessions across the country
- School visits, ward visits and parent support at NID clinics
- Member of international collaboration (12 countries incl USA, UK, NZ, Russia, India) managing children with ARM/ Hirshprung
- Networks with Human Services child protection, education system, allied health system and extensive community agencies