



Invisible Illness

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



Neuronal Intestinal Dysplasia (NID)

Organisations who wrote / approved the information

Nidkids Support Group Pty Ltd & Royal Children's Hospital

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Neuronal Intestinal Dysplasia (NID)

A: FACTS ON THE CONDITION

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

Childhood constipation may be due to either difficulty evacuating bowel motions, with faeces held up in the rectum for long periods, or due to slowed movement through the entire large bowel (colon). This second type of abnormality is termed “slow transit constipation”. Some of these children with slow transit constipation also have an abnormality of the nerves supplying the bowel, which is termed “Neuronal Intestinal Dysplasia” or “NID”. This tends to respond poorly to standard treatment.

Prevalence

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

Signs and Symptoms

NID 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.

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

NID 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 (Appendicostomy)

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.

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

1. Effects on the individual

NID patients differ in age and sex, and their distress can take on many forms. The child may suffer from anxiety; feelings of sadness, depression and anger arise. Children may become obviously tearful and withdrawn; suicidal thoughts or attempts can occur. They can also 'act out' aggressively as a reflection of their feelings. They may also show poor concentration, attention or learning problems at school.

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.

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:

JT is a 10 year old with NID. He 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. JT 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. JT 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 NiDKiDs Support Group Ltd website www.nidkids.org.au

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D: FURTHER INFORMATION

1. Organisations, including services and resources available

Nidkids is a registered support group:

NiDKiDs Support Group Ltd
24 Main St
Lilydale, Vic. 3140

Phone: 03 9738 8533 or 03 9738 8534

Fax: 03 9738 8501

Email: mail@nidkids.org.au

Website: www.nidkids.org.au

Services and available resources

Information: Brochures, kits, video and Internet

Peer Support: National office phone support and meetings when required

Workshops: Visits to Royal Children's Hospital, lab tours, awareness week, seminars (these are advertised in the monthly newsletter)

Bottom Line Newsletter: contains information about the latest research, doctors' reports, parents' stories, as well as upcoming events.

