

PAEDIATRIC STOMAL THERAPY

It is about twenty-five years since I (*Judy Wells*) started working as a paediatric Stomal Therapist. I can remember the first day I walked into the department - there were open shelves with boxes piled high. They looked like shoe boxes. Now, a quarter of a century on, some appliance boxes still resemble shoe boxes but things have changed - both appliance availability for little kids and surgical management.

The appliances for babies and children have changed. No longer do we tailor-make tiny bags for our premature infants of twenty-four to twenty-five weeks using cryovac tubing and wafers with double sided tapes. We have prem bags and bags for term babies - all shapes and sizes; with or without filters, clear, opaque, some even teddy bear motifs, one-piece and two-piece. It's a far cry from the early eighties when there were barely any options.

Believe it or not the old, rubber, reusable Downs bags and flanges that were stuck to the skin using a special adhesive, were still used on a few patients when I first began at the Royal Children's Hospital. Now silastic plugs and clear dressings are available on the Stoma Appliance Scheme for tiny appendix stomas to keep them open for washouts.

Surprisingly, maybe, the reasons why babies/ children/adolescents have stomas have not changed all that much. Stomas in children are mainly temporary in 90-95% of cases, covering periods of time from a few weeks to a few years. Stomas are necessary for babies who are born with congenital abnormalities such as Hirschsprung's disease, a condition where the nerves that make the bowel muscles contract and push the bowel contents along are scant or absent in a section of bowel. This occurs in 1 in 5000 live births and is more common in boys than girls.

Imperforate anus is another reason for a stoma in a baby. In this condition the anus is not patent. It might be formed but covered by skin or the rectum may end higher up the bowel with missing nerves and muscles that regulate bowel control.

Necrotizing Enterocolitis is more common in very premature infants whose blood supply to the gut is not quite properly formed when they are born so patches of the gut die because of inadequate blood supply. They can get very sick quickly and may require emergency surgery and a temporary stoma.

Meconium Ileus sometimes occurs in babies who are born with cystic fibrosis. The meconium, or first 'poo' is very sticky and plugs the small bowel causing an obstruction. Again sometimes removal of the 'plugs' and a temporary ileostomy is the best way to manage these little babies.

Occasionally some children have temporary stomas after side effects on the bowel tissue from chemotherapy for leukaemia or other types of cancers.

Trauma: Given that kids will be kids, some kids may have slipped off fences onto palings or fallen off bikes and landed awkwardly but fortunately, this is rare in my experience.

Crohn's disease or ulcerative colitis are two conditions that are more common in adults but do occur in children, more likely adolescents, and if treatment fails they may require a temporary colostomy or ileostomy.

Urine stomas are not very common in children although thirty to thirty-five years ago and earlier, many of the children born with Spina bifida had an ileal conduit fashioned to prevent kidney damage as they grew up. There are still children born with this condition

but now they have catheters inserted through the urethra into the bladder to drain the urine four or five times a day which has proven to be very effective in preventing kidney damage.

Some children have an obstruction in a ureter or urethra for different reasons or a bladder with damaged nerve supply. They may have a stoma called a vesicostomy, which is an opening on the tummy directly into the bladder. This ensures the bladder keeps empty and prevents the urine from tracking back up to the kidneys which if not treated is really detrimental for kidney function. Some children wear a bag over the vesicostomy but it is often in a very awkward spot midway between the symphysis pubis and the belly button.

There is a congenital condition known as ectopic bladder or bladder exstrophy. In this condition babies are born with the bladder exposed on the abdomen and there are associated abnormalities with the genital organs. These children face many surgical reconstruction procedures, both as new-borns and further down the track. In the past many of this group of children had urinary stomas, however, nowadays many are able to have a continent urinary diversion as described later in this article. Very rarely some children get a type of bladder cancer known as rhabdomyosarcoma. In some cases, all or most of the bladder may be removed and the children may have a ureterostomy or opening.

There has been a big shift away from formation of 'traditional' type stomas for children who have problems with bowel and/or bladder control or really bad constipation problems. Roughly about a third of the Victorian Children's Ostomy Association members have either a Malone Stoma, which is an appendix stoma, where a small catheter is passed through this opening and a washout solution is instilled directly into the caecum enabling the bowel to empty the normal way. A silastic plug may be necessary to prevent this tiny stoma from narrowing.

The other type of stoma is known as a Mitrofanoff Stoma and in this instance the appendix usually [but surgeons can use a piece of bowel or ureter] is isolated from the caecum and one end is tunnelled through the muscular bladder wall and the other end is brought out as a tiny stoma. A catheter is passed through this stoma to completely empty the bladder at intervals thus preventing kidney damage. Both the Malone Stoma and the Mitrofanoff Stoma have 'valves' to prevent any leakage of bowel contents or urine. These stomas are usually sited on the right side, low down on the abdomen close to where the appendix is or in the belly button. They are very hard to find as they are so small and, if in a belly button they are completely invisible.

One kid I know told his classmates that he could do magic and get urine out of his belly button. He would charge 50c and take them into the toilet and drain 400mls into the bowel from his belly button!

Of course as with any surgical intervention there are some complications that can occur but for some children a Malone or Mitrofanoff Stoma can make a huge difference to their quality of life. Incontinence is hugely damaging to a child's self-esteem. There are a few children - really special ones, who have both these type of stomas. Another huge plus is that these stomas are very easy to manage and for some children they mean they can manage their bowel and bladder routines independently. They can go on sleepovers and out with friends without worrying about wetting or soiling. There are not the huge costs of nappies and endless loads of washing for parents.

Paediatric stomal therapy often flows into continence management. In some cases, children who may have been born with imperforate anus or Hirschsprung's disease and

had stomas and pull through surgery at a few months of age or those who were born with Spina bifida and have damaged nerve supply to the bowel, or a third group of kids who have slow transit constipation with overflow soiling, struggle with bowel control. There are various approaches including dietary modification, laxatives, enemas, interferential therapy etc. that we try but when it is apparent that nothing is working and the kids are at risk of being teased at school or becoming self-conscious or angry, it is great to have something to suggest that is not too major and often can greatly improve their continence.

'There are two options to look at when nothing seems to be helping. Recently, an easy to manage, large volume bowel washout system has been trialled with really encouraging results. Not all children and/or parents can manage this as a large tube is used and it can be uncomfortable as well as time consuming. The other option which, with patience and perseverance usually has good results long term is the Malone Stoma. There are numerous suggestions for various washout solutions to try.

I cannot reflect about paediatric Stomal Therapy over the last twenty-five years without including a bit about buttock care. So many babies have skin breakdown problems post stoma closure. A combination of corrosive output, frequent bowel movements and teething can cause havoc with a baby's skin. Often crater like ulcers appear or the skin breaks down and becomes eroded and bleeds and is incredibly painful despite the parents' best efforts, sometimes nappy changes every fifteen minutes. We try to stress the importance of applying barrier creams etc. to prevent the skin breaking down and have a strict buttock care regime commenced straight after stoma closure surgery. We use barrier creams/wipes, hydrocolloid powders etc. There are new and improved creams available now and severe nappy rash is nowhere near as prevalent as it once used to be. There is a cream available from a few outlets in Australia called Ilex that often works very well as it adheres to eroded broken down skin and it can make a huge difference. Some mothers have tried mixing various creams with powders etc. and have had good results. My advice is to treat sore bottoms post stoma very seriously, seek early advice and if one thing does not work go back and try something else. There are excellent web sites on 'butt balms'. Make sure you read application instructions as Ilex can make things worse if attempts are made to clean it all off at each nappy change.

I am not sure yet how things will change in the world of paediatrics over the next 25 years. I will be a really old bag lady by then! I do know that one of these days we may do our first intestinal transplant at the Royal Children's Hospital. One thing you can be sure of is things will not remain static.

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