

# HIRSCHSPRUNGS DISEASE PASSPORT



**Patient name:** \_\_\_\_\_

**Date of Birth:** \_\_\_\_\_

**GP :** \_\_\_\_\_

**Consultant:** \_\_\_\_\_

### Contact details

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## INTRODUCTION

This booklet was compiled by the Colorectal/ Stoma Clinical Nurse Specialists at Children's Health Ireland at Crumlin to give parents and professionals a guide to the treatment of Hirschsprungs Disease. This booklet should be retained by the parent and used to keep track of their child's treatment.

It is a guide and should be treated as such. Each patient is an individual and specific care will vary. Please discuss any concerns you have with your nurse specialist or doctor.

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## DEFINITION

Hirschsprungs Disease is a congenital disorder of the bowel. This means the disorder has been present since birth. There is an absence of nerve cells in the bowel wall. These nerve cells are called ganglia. These ganglia are responsible for movement of the bowel called peristalsis. Peristalsis moves the poo along the bowel. The portion of the bowel that does not have the ganglia is called 'aganglionic'. This affected portion can vary in length. As a result of this aganglionic portion poo does not move through the bowel.

After birth, some or all of the following signs and symptoms may be present. Breast fed babies may present slightly later.

- A long delay or failure to pass the first bowel motion known as meconium
- Vomiting (may be green – bilious)
- Poor feeding
- Swollen belly (distended abdomen)

### **It is unusual for hirschsprungs to present in older children**

Older children may show a delayed onset of symptoms, such as the following:

- Chronic constipation
- Poor growth and development
- Swollen belly (distended abdomen)

The condition can be hereditary and occurs in the first few weeks of pregnancy. The cause is unknown, but it is not due to anything which has been done or not been done by either parent. Approximately 1 in 6450 births is affected, generally more boys than girls and those with Down's syndrome.

Once a diagnosis of Hirschsprungs is made the treatment pathway for your baby will depend on the length of the bowel affected by Hirschsprungs Disease.

- SHORT SEGMENT HIRSCHSPRUNGS WILL BE TREATED WITH RECTAL WASHOUTS
- LONGER SEGMENT HIRSCHSPRUNGS MAY REQUIRE A STOMA.

## TREATMENT PATHWAY

Referral to OLCH with? HD

Decompress the bowel

Rectal washouts +/- dilatations

Stoma

Rectal biopsy

Diagnosed with Hirschsprungs Disease

Rectal washouts +/- dilatations

Stoma care

Pull through Surgery +/- stoma closure  
Determine length of bowel involved

EUA 2-3 weeks post-surgery

Dilatation

Stoma care

OPD

Wean dilatations

Plan stoma closure

## ENTEROCOLITIS

Enterocolitis is a complication that can occur at any time in a child with Hirschsprungs Disease. The reason is not fully understood but is thought to be due to an overgrowth of bacteria in the bowel. It is important to be aware of the signs and symptoms (see below) and to act quickly if Enterocolitis is suspected.

### Signs and symptoms:

- Swollen belly (distended abdomen)
- Vomiting
- Explosive watery diarrhoea or no passage of stool at all
- Discomfort (drawing knees up)
- Foul-smelling wind
- High temperature

If you are concerned about any of these symptoms or your baby seems unwell it is very important that you seek medical advice immediately and explain that your child has Hirschsprungs. Your child is at risk of dehydration and will need to be treated as soon as possible. Treatment includes rectal washouts, antibiotic treatment and fluids via a drip.

## RECTAL WASHOUTS



A Rectal Washout is where the lower bowel is emptied and cleaned with the use of a catheter and saline solution.

It is necessary for your baby to have a rectal washout because, at present, your baby is unable to empty their bowel adequately without help.

Washouts are required until at least the pull-thru surgery and may be required after it. This depends on certain circumstances such as recurrent enterocolitis or incomplete emptying.

If your baby is upset when preparing for a rectal washout soft music, your voice or a soother may help to settle them. Do the washout when your baby is most relaxed, usually after a feed.

However, if your baby is very distressed or appears to be in pain, stop the washouts and contact your Colorectal CNS or relevant Surgical Team.

Before starting, gather the equipment needed and ensure the room is warm and baby is comfortable.

## EQUIPMENT

- Non sterile gloves
- Incontinence sheet
- Sterile 0.9% NaCl (place unopened container of saline into a bowl of warm water)
- Sterile Vygon Vesical Catheter size \_\_\_fr Catheter tip 60ml syringe
- KY jelly
- Bowl
- Soap and water/ baby wipes to clean

## WHAT TO DO

- Wash hands
- Fill syringe with saline (amounts depends of weight of your child, this will be decided before d/c home)
- Attach catheter to syringe
- Push saline through to end of catheter
- Lubricate end of catheter with KY Jelly
- Remove baby's nappy and clean bum
- Wash hands and put on gloves
- Insert catheter into anus about 3 – 5 cms
- If no resistance is felt insert in further as directed by the CNS
- Do not advance the tube if resistance is felt
- Slowly instil the saline (10- 20mls at a time, over 5-10 seconds)
- Keep the catheter in place and remove the syringe and place the end of the catheter in the bowl after every 10- 20mls
- Wait for the water to return along with stool
- Massage left side of belly, move catheter in and out to ensure fluid returns out
- When finished the washout remove catheter, clean bum and apply cream if required. Catheters are one use only. Syringe can be washed in hot soapy water and changed weekly.
- Discard equipment in household waste and empty contents of bowl into the toilet and wash your hands

## TIPS

- You may be instructed to insert an empty catheter first before inserting the saline, this is to release any trapped wind.
- Move the catheter around to ensure it doesn't get blocked.

If there is no return of fluid or stool, then the catheter maybe blocked. Remove and unblock it by pushing saline through the tube. Continue with washout.

Massage the abdomen during the washout to encourage emptying.

Take your time doing the washout.

Contact the Colorectal/ Stoma CNS if you are experiencing difficulties with the washouts.

## PRODUCT CODE

Catheter: \_\_\_ fr, # \_\_\_\_\_ Syringe: \_\_\_\_\_

This will be prescribed and can be sourced from your PHN before discharge home.

## WASHOUT ROUTINE

Frequency of w/out: \_\_\_\_\_/day

Amount of saline per w/out: \_\_\_\_\_mls Size catheter: \_\_\_fr

## DILATATIONS



You have been asked by your surgeon to perform anal dilatations for your child in order to stretch the anus.

The purpose of stretching the anus is so that your child will be able to pass stool (poo).

A member of the surgical team will do the first anal dilatation and decide what size dilator to use and how far to insert it.

You will be shown by the CNS/doctor how to perform the anal dilatations when your child is in hospital.

This can initially be distressing for both parents and baby/toddler, but soon becomes less stressful as you become more confident and your baby/toddler gets used to it.

Dilatations usually need to be done two or three times a day. The length of time that you will have to do them will be until corrective surgery has been performed. The **Anal Dilators** are supplied by the hospital. When you come to clinic they can be exchanged for the next size if necessary.

### **CARE OF THE ANAL DILATOR**

- Wash anal dilator after each use
- Wash in warm soapy water
- Drying with a paper towel
- Store in a dry, safe place.
- Anal dilators do not need to be sterilized.

### **POTENTIAL PROBLEMS**

#### **Bleeding**

Your child may have a very small amount of bleeding following anal dilatation and/or some streaks of blood in their next poo after dilatation. This is quite common, especially if your child has had anal/rectal surgery.

If you notice a larger amount of blood than you have been advised is normal by your surgeon/nurse, **STOP** anal dilatation and contact the number provided or your GP where further advice will be given.

#### **Pain**



Your child may experience discomfort with anal dilatations usually when increasing the dilator size to larger sizes. This should subside over a few days as the anus stretches. If you notice that your child is experiencing pain or great discomfort **STOP** anal dilatations and contact as above.

### Insertion difficulties

If at any time during the anal dilatation you are having difficulty with inserting the dilator, **STOP**. Forcing the anal dilatation will cause pain. The anus may have narrowed and you will need to go back to a smaller size. Contact the above number for further advice.

## STOMA CARE

The word stoma comes from the Greek meaning mouth or opening. This allows the poo to come out and so will keep the bowel decompressed (deflated).

There are 2 types of stomas:

- **Colostomy:** A portion of the large bowel (colon) is brought out through the abdominal wall and is normally sited in the left lower side (iliac fossa). Any part of the large bowel (transverse, descending or sigmoid colon) may be used. A mucous fistula (passage) is also formed alongside or slightly away from the colostomy. This is the non-functioning part of the bowel, it will produce mucous, hence the name.
- **Ileostomy:** A portion of small bowel (ileum) is brought out through the abdominal wall and is normally sited in the right lower side (iliac fossa).

### Looking after the stoma

It's important to remember that your child's stoma is painless. It may look red and sore but there are no nerve endings to pain in the stoma. Your nurse will teach you how to care for your child's stoma and with a little practise you will be able to change the stoma bag.

The stoma bag is an appliance made of special plastic designed to fit around the stoma to collect the poo and protect the skin around the stoma (peristomal skin). The bag will need to be changed every 2-3 days or sooner if it leaks. It will need to be emptied by the drainable end every 2-3 hours or when you change the wet nappy.

### EQUIPMENT

- Warm water & Gauze squares
- Remover spray & wipes
- Protective barrier spray or wipe
- Paste or seal if using
- Fresh bag cut to size (using template) & end closed

### WHAT TO DO

- Wash hands
- Remove old bag using remover spray, gently pulling away from top end first
- Dispose of bag into a nappy sac
- Wipe off any residue or poo or glue with remover wipe
- Wash skin with warm water and gauze
- Dry skin with clean dry gauze
- Apply protective barrier
- Allow to dry
- Apply seal or paste if using right up against the stoma to protect the peristomal skin

- Check size of stoma bag hole before removing backing and if correct size remove backing and apply bag. Take your time making sure the bag is well adhered to the skin.
- Check that there are no creases in the base of the bag
- Dispose of nappy sac in domestic waste and wash your hands
- Apply nappy

### **Points to remember**

- The stoma will change size in the first few weeks so the template for cutting the stoma bag will change.
- The colour of the stoma will change when your child cries, it should return to a normal pink healthy colour when your child is settled.
- If the bag leaks it needs to be changed. If this is a continual problem, then your stoma nurse needs to review your child to overcome this problem.
- If the skin around the stoma is getting sore you must contact your stoma nurse to prevent it getting any worse. It will initially be red when you take the bag off but this will disappear after a couple of minutes.
- It is normal to see a small amount of blood on the gauze when you are cleaning the stoma. The stoma has a good blood supply and so this is a normal healthy sign.

### **Potential problems**

#### **Skin irritation**

When you remove the bag first you will notice the skin is red, this will calm down after a minute or two. This redness is from pulling the bag off the skin. However if the skin remains red and irritated looking there may be a reason why:

- The bag is leaking and poo is sitting on the skin causing the irritation.
- It could be due to an allergy to a product.
- Changing the bag too often or rubbing the skin too much to clean it can cause irritation.
- If the child is teething skin can become more delicate.
- Excess sweating.
- Fungal infection.

Call you CNS and arrange a review. These problems can be easily sorted.

#### **Loose stool**

If you notice the poo is watery and has increased in volume, please seek medical advice. Your child is at risk of dehydration and will need to be reviewed. Babies require a certain level of sodium (salt) in their body to utilise their feeds. If they have excess losses from their stoma they may be losing excess sodium and may have low sodium in their urine. They may show signs of poor or no weight gain. Your baby will need to have a blood and urine test to check sodium levels. Usually a supplement will solve the problem.

#### **Prolapse**

This is when a bit more bowel comes out via the stoma. This can be alarming to see but as long as the bowel is pink and healthy looking and it continues to function it is not an emergency situation. This is a common problem. The bag may need to be changed to a larger size to accommodate the larger stoma. Contact your Stoma CNS to arrange a review.

### Retraction

This is when the stoma is flush with the skin or sunken below skin level. Once the bowel is pink and healthy looking and it continues to function it is not an emergency situation. However, this can cause problems with bag leakages. Contact your Stoma CNS to arrange a review.

### Pancaking

This is when the stool collects around the top of the bag and does not drop down into the bag. It is caused by a negative vacuum in the bag itself. Try putting a few drops of baby oil into the bag or a piece of cotton wool. If there is a filter on the bag, partially cover it with the sticky tab supplied in the box.

### Ballooning

This is when the bag blows up due to wind being passed into the bag and becoming trapped. The end of the bag needs to be opened to allow the wind out. If it is a problem you may need to change the bag that you are using. Contact your Stoma CNS to arrange a review.

### Stenosis

This is when the opening of the stoma narrows and leads to difficulty in passing stool. This can lead to abdominal pain and the stoma not working at all. You will need to seek medical advice. It is rare that this can happen.

## SURGERY

For most children born with Hirschsprungs Disease, surgery will be carried out at around 3-6 months of age. Surgical procedures are often carried out at different ages according to the child's condition and Surgeon. The surgery is called a PULL-THROUGH and involves removing the Hirschsprungs affected portion of bowel and "pulling-through" the unaffected ganglionic portion. This may result in a temporary stoma in some cases.

### Potential problems following 'pull-through' may include:

- Loose poo
- Nappy rash (due to frequent loose poo)
- Issues with toileting training (soiling, constipation)
- Enterocolitis

### Main types of operation

- Open
- Keyhole (Laparoscopic)
- Transanal (through the bottom)
- Combination of the above

### Names of operations

- Soave
- Swenson
- Duhamel

## NAPPY CARE

Following Stoma closure and Pull Thru surgery your child may suffer from nappy rash due to frequent exposure to stool.

Nappy rash can vary from mild redness to severe skin damage. This can often cause the child to experience pain and discomfort.

### **"PREVENTION IS BETTER THAN CURE"**

#### **PREVENTION OF NAPPY RASH**

- Immediately after surgery ensure that a barrier cream is applied to your child's bottom
- Change your child's nappy as soon as possible following a bowel movement
- Clean your child's bottom thoroughly with warm soapy (non-perfumed) water and a soft cloth or water wipes. Try to avoid using standard **BABY WIPES**
- Apply barrier creams/paste/powder as directed by your Stoma/Colorectal CNS

#### **HEALING NAPPY RASH**

- Clean your child's bottom gently with warm water and a soft cloth, and pat dry gently
- If cleaning with a cloth becomes too painful, using the shower to rinse off the poo can help
- Bath daily to remove all creams/ointments
- Following removal of creams or after bathing, exposing the child's bottom to the air can help "dry" the skin
- If skin is not healing or there is evidence of infection (bright red spots on bottom) it is advisable to have your GP/CNS check it as it may need treatment with an antifungal cream

#### **RECOMMENDED TREATMENTS**

- Ilex paste
- Metanium
- Orobace Paste
- 3 in 1 (mixture of vaseline, orobase + metanium- mix equal amounts of each together in a clean tub)
- Sudocreme/Bepanthen (used for mild irritation)
- It is advisable to apply a layer of waterproof barrier over creams/pastes e.g. Vaseline
- If skin is to "wet" and prevents creams/pastes from sticking a light dusting of Caldesene/Orohesive Powder may be advised by your CNS.
- For treatment of a bacterial infection an antibiotic cream will be prescribed
- For treatment of a fungal infection an antifungal cream will be prescribed

#### **REMEMBER:**

In the case of the following, it is advisable to apply a barrier cream/paste prophylactically to your child's bottom:-

- Teething
- Change of diet
- Diarrhoea
- Antibiotics/Laxatives

### **DIRECTONS FOR USING ILEX**

- Clean your child's bottom as advised
- Firstly, apply a non-sting barrier film product and allow to dry
- Apply a layer of **ILEX** over the area of bottom needing protection. Allow 30seconds to dry
- Apply a layer of **VASELINE** over the **ILEX** and surrounding skin to prevent the nappy from sticking to the **ILEX**.
- When cleaning, only the stool should be wiped off using a soft cloth and water leaving the **ILEX** intact.
- Reapply additional **ILEX** if required, then reapply **VASELINE**. (This is to minimize further trauma to the skin)
- The **ILEX** should be entirely removed once a day using a soft cloth with a good amount of mineral/baby oil or in the bath.

## **TOILET TRAINING**

Choosing the right time to start toilet training is not always easy, especially if your child has had bowel surgery. Between the ages of 2 and 3 is usually a good time to start but each child is different. Things to consider when deciding if your child is ready for toilet training can include:

- Your child is emotionally ready (if the toddler is going through an aggressive or resistant phase..terrible 2's!!it is probably best to wait until this has passed.)
- Your child can understand simple instructions.
- Your child is able to sit and get off the potty with only a little help
- Your child can pull their pants up and down with a little help
- Have no major upheavals planned for at least a week to give a 'clear run' at toilet training.

### **TIPS FOR TOILETING**

- Make sure the bathroom is warm and inviting! Close the windows and maybe put up some posters for your child to look at.
- Take advantage of the body's natural 'gastro colic reflex'. This is strongest in the morning and about 20-30 minutes after main meals.
- Try to keep to a routine, using the toilet around the same times every day and also when your child says they feel the need to go – always respond to the body's urge to poop!
- Stay with your child. Do not leave the child sitting on the toilet by themselves for long periods of time.
- Ensure the toilet is comfortable to sit on. Some children fear that they will fall into the toilet and so it is important to get an add-on seat for smaller children.
- A footstool is very important to ensure your child has good support for their feet.
- Put some toilet paper into the bowl first so that there is no splash back when a pooh is passed. Some children get a fright if there is a splash!
- When sitting on the toilet your child should be able to lean forward and rest their elbows on their knees with their knees higher than the hips
- Your child should be relaxed when sitting on the toilet and not straining.
- Talk to your child when following these steps so that they know what you are trying to achieve.

## Correct position for opening your bowels

### Step one



Knees higher than hips

### Step two



Lean forwards and put elbows on your knees

### Step three



Bulge out your abdomen  
Straighten your spine

### Correct position



Knees higher than hips  
Lean forwards and put elbows on your knees  
Bulge out your abdomen  
Straighten your spine

Reproduced by the kind permission of Ray Addison, Nurse Consultant in Bladder and Bowel Dysfunction.  
Wendy Ness, Colorectal Nurse Specialist.

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## CONSTIPATION

Once all your Child's surgery has been completed, many families assume that their child will have no further problems. However we know from experience that the majority of children experience some degree of constipation or diarrhoea and have trouble establishing good bowel control following reconstructive surgery.

It is very important that you observe your Child's bowel habits and seek advice from your colorectal nurse or doctor if they are not having a regular poo or if the poo is becoming difficult to pass. If required a structured bowel management programme should begin early in order to prevent major problems developing at a later age. This includes the following:

- Fluid and diet diary
- Medication
- Toileting regime

### DIFFERENT TYPES OF POO

The Bristol stool chart is used to describe the type of stool your child is passing. It is important that you know what type of poo that is being produced as it can tell your doctor a lot. For instance, type 1 can indicate constipation as they are generally hard little lumps that look like rabbit droppings. Also some children will pass type 7 poo along with type 1 and this can be overflow diarrhoea with constipated stool. Involve your child with deciding what their poo looks like and keep it recorded in the diary section.

Type 3 & 4 are the ideal poo as they are soft and easy to pass.

### Bristol Stool Chart

Type 1		Separate hard lumps, like nuts (hard to pass)
Type 2		Sausage-shaped but lumpy
Type 3		Like a sausage but with cracks on its surface
Type 4		Like a sausage or snake, smooth and soft
Type 5		Soft blobs with clear-cut edges (passed easily)
Type 6		Fluffy pieces with ragged edges, a mushy stool
Type 7		Watery, no solid pieces. <b>Entirely Liquid</b>

## FLUIDS & FIBRE

### What goes in, must come out!


It is imperative that your child has a healthy well balanced diet. Take note over a few days of what your child is eating and drinking – are they honestly reaching the recommend fluid and fibre intake for their age? It can be difficult to achieve this but make small changes every day and gradually habits will change.

### TIPS FOR INCREASING FLUIDS

- Encourage plenty of non-fizzy drinks for example, water, fruit juice and squash.
- Avoid excessive milk consumption as children can easily fill up with milk resulting in a poor dietary intake.
- For children who find it difficult to increase the amount they drink, try to include foods that contain high fluids e.g. gravy, sauces, soups, custard, jelly, ice lollies and fruit

For babies, try giving cooled boiled water between feeds

### Fluids



	Total water intake per day, including water contained in food	Water obtained from drinks per day
<b>Infants 0–6 months</b>	700 ml assumed to be from breast milk	
<b>7–12 months</b>	800 ml from milk and complementary foods and beverages	600 ml
<b>1–3 years</b>	1300 ml	900 ml
<b>4–8 years</b>	1700 ml	1200 ml
<b>Boys 9–13 years</b>	2400 ml	1800 ml
<b>Girls 9–13 years</b>	2100 ml	1600 ml
<b>Boys 14–18 years</b>	3300 ml	2600 ml
<b>Girls 14–18 years</b>	2300 ml	1800 ml





## **FIBRE**

### **HOW TO CALCULATE HOW MUCH FIBRE YOUR CHILD NEEDS:**

Child's age in years + 5 grams for children over 2 years of age.

E.g: if your child is 7 years old, then you calculate it as

$$7 + 5 = 12.$$

Therefore a 7 year old should be eating 12 grams of fibre a day



### **TIPS FOR INCREASING FIBRE**

Try to include some of the following fibre containing foods at each meal/snack:-

- Add linseed to breakfast cereals and yogurts (drink plenty of water if adding linseed to cereal)
- Wholemeal bread or Best of Both breads
- Wholemeal pasta and brown rice
- High fibre biscuits such as digestive, fig rolls, cereal and muesli bars
- Homemade muffins with wheatbran added
- Fruit and vegetables
- Pulses e.g. baked beans, kidney beans, chickpeas and lentils. These can often be added to Bolognese, soups, sauces, stews, casseroles for example.
- Potatoes and jacket potatoes with skin left on

A high fibre and fluid diet is a healthy diet and is suitable for all the family. You should encourage a regular meal pattern and increase the whole family's fibre and fluid intake at every meal.

by doing this you will increase the water content of stools making them softer and easier to pass.

The next few pages detail the amount of fibre in common popular foods. Try at least one new food a week and give it a few tries, don't give up after the first refusal, it can take a few attempts to develop a taste.

## FIBRE CONTENT

### BREAKFAST CEREALS



Type	Portion	Fibre g's
All- Bran	Small bowl	7.2
Bran buds	Small bowl	6.6
Mini shredded wheat	Small bowl	3.4
Bran flakes	Small bowl	2.6
Raisin splitz	Small bowl	2.3
Muesli	Small bowl	2.0
Sultana bran	Small bowl	2.0
Weetabix	1 biscuit	1.9
Fruit 'n' fibre	Small bowl	1.4
Country store	Small bowl	1.2
Corn flakes	Small bowl	0.2

## NUTS



### OVER 5'S ONLY DUE TO RISK OF CHOKING!

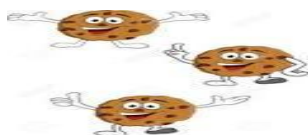
Type	Portion	Fibre g's
Peanut butter	Thickly spread	1.4
Almonds	6	1.0
Peanuts	10	0.8
Brazils	3	0.6

## RICE & PASTA



Type	Portion	Fibre g's
Wholemeal spaghetti	3 tablespoons	3.1
Brown boiled rice	2 heaped tablespoons	0.6

## BISCUITS & PASTRIES



Type	Portion	Fibre g's
Wholemeal scone	1	2.6
Cereal bar	1	1.0
Oat cakes	1	0.7
Jacobs fig roll	1	0.7
Cracker	1	0.4
Rich Tea	1	0.4
Digestive biscuits	1	0.3

## BREAD



Type	Portion	Fibre g's
Wholemeal pitta	1 mini	1.8
Wholemeal	1 small slice	1.5
Brown	1 small slice	0.9
High fibre white	1 small slice	0.8
Hovis	1 small slice	0.8

Type	Portion	Fibre g's
Broad beans	2 tablespoons	7.8
Red kidney beans	2 tablespoons	4.3
Butter beans	2 tablespoons	3.7
Peas	2 tablespoons	3.0
Baked beans	2 tablespoons	3.0
Chick-peas	2 tablespoons	2.9
Potatoes (baked with skin)	1 small	2.7
Corn-on-the-cob	1	2.7
Broccoli Tops (raw)	2 spears	2.4
Carrots	2 tablespoons	2.0
Spinach	2 tablespoons	1.7
Lentils split (boiled)	2 tablespoons	1.5
Potatoes (new)	2	1.2
Oven chips	Small portion	1.2
Cabbage	2 tablespoons	1.1
Leeks	Stem	1.1
Sweetcorn (canned)	2 tablespoons	0.9
Turnip	1 tablespoon	0.8
Beetroot	4 slices	0.8
Tomatoes (Raw)	1 small	0.7

## FRUIT



Type	Portion	Fibre g's
Pear	1 medium	3.3
Dates (dried)	5	3.0
Avocado	½	2.6
Prunes (dried)	5	2.3
Orange	1 small	2.0
Blackberries	10	1.5
Melon-cantalope	1 slice	1.5
Apple	1 small	1.3
Fruit cocktail	Small bowl	1.2
Kiwi fruit	1 medium	1.1
Banana	1 medium	1.1
Peach	1 medium	1.1
Raspberries	10	1.0
Pineapple	1 large slice	1.0
Grapefruit	½	1.0
Mango	1 slice	1.0
Strawberries	5	0.7
Grapes	10	0.6
Raisins	1 tablespoon	0.6
Tangerine	1 small	0.6
Plum	1 small	0.5

## BOWEL MANAGEMENT

Despite good fluid and diet intake sometimes some children with Hirschsprungs may still suffer with soiling and/or constipation. This is uncommon but it can be a major source of stress for the child and parents. With early assessment and intervention the child can be socially clean and free from constipation and soiling. An individualized bowel management program will be put in place once you have met the Colorectal Surgeon and your Colorectal/Stoma CNSp.

Every bowel management program requires patience, dedication and time. Your child will be followed closely by your CNSp and effort will be required you and your child.

Initially as part of the assessment you and your child will be required to fill out a detailed fluid, diary and bowel chart for a period of time.

Once the assessment is completed your child's bowel management plan will be devised with you and your child's input.

In addition to toilet training routines there are three main bowel management options:

- **Medication**
- **Transanal irrigation**

A combination of these options may be appropriate for your child

## Medications for Constipation

There are a variety of medications/laxatives that the doctor may prescribe for your child to help treat their constipation. These medications may need to be taken regularly for some time before your child's bowels return to normal. They will not make your child's bowel "LAZY".

The types of laxatives available for children are divided into different groups depending on how they work:

### **BULK-FORMING LAXATIVES**

- Used if fibre intake is low
- Increase size of stool so stimulating peristalsis
- Must have an adequate fluid intake
- Do not take before bedtime
- Once mixed with water, drink immediately
- Used in management of haemorrhoids & anal fissures
- E.G: Fybogel (over 6years of age only)

### **STIMULANT LAXATIVES**

- Stimulant laxatives which stimulate contractions of the muscles in the bowel, shortening the time it takes stool to pass through the bowel.
- Some can take 8-12 hours to work
- E.G: Senna (Senokot), Bisacodyl (Dulcolax), Docusate Sodium, Glycerol, Sodium Picosulphate

### STOOL SOFTENERS

- As the name suggests, these products ease the process of passing stool by softening the stool and lubricating its passage through the anus.
- E.G. Liquid Paraffin, Olive Oil Enema

### OSMOTIC LAXATIVES

- This group of medications work by drawing fluid from the body into the bowel or by retaining the fluid it is taken with, so softening and increasing the bulk of the stool.
- Some of these medications can take 24-48 hours to act.
- E.G: Lactulose, Macrogols (Movicol), Magnesium Salts, Phosphates (Fleet), Sodium Citrate (Micolette Micro-Enema)

**PLEASE KEEP MEDICATIONS LOCKED AWAY FROM CHILDREN IN A SAFE PLACE**

**IF YOU ARE CONCERNED ABOUT THE EFFECT OF LAXATIVES ON YOUR CHILD AT ANY TIME YOU SHOULD CHECK WITH YOUR DOCTOR.**

**DO NOT STOP MEDICATIONS WITHOUT CONSULTING YOUR HEALTHCARE PROVIDER**

### TRANSANAL IRRIGATION

Transanal Irrigation is simply a way to empty the rectum so to keep your child socially clean i.e. to remain free of soiling accidents. The aim of the irrigation is to do the washout daily with a solution of water, salt and sometimes a stimulant medication to stimulate the bowel and empty it of stool. This washout is performed on the toilet.

There are three different types of equipment that may be used to perform this irrigation:

- The Willis System
- Peristeen
- Braun Iry Pump

With the help of your CNSp you and your child will decide which equipment suits your child best. You will be given specific instructions on the type of washout equipment your child will be using.

### POTENTIAL PROBLEMS

- **BLEEDING:** slight bleeding after the washout can occur and this can be due to local trauma. Ensure you are lubricating the cone or catheter adequately and never use force to insert. If bleeding is profuse STOP WASHOUT and SEEK MEDICAL ADVICE IMMEDIATELY.
- **POOR RESULTS:** this can be due to a build-up of stool in the rectum so contact your CNSp to discuss same. You may need to adjust volume and type of fluid for washout or commence on a laxative.
- **SOILING BETWEEN WASHOUTS:** frequency or volume of washouts may need to be adjusted, contact your CNSp.
- **FEELING FAINT DURING WASHOUT:** this may be due to the stimulant added to your washout or the fluid going in too quickly. Discuss with your CNSp.
- **BOREDOM:** sitting on the toilet for a long period of time can become boring for kids. Organise something for them to do at this time, homework, play a board game etc. make sure they don't feel shut away and might like to leave the bathroom door open.





**KEEP A RECORD OF IMPORTANT DATES**

Procedures	
Biopsy	
Stoma	
Pull thru	
Stoma Closure	

Out Patients	
Name	Date

### YOUR QUESTIONS




## Your Diary



- Update diary daily with your child, encouraging them to participate
- It is easier to see a change in pattern when it is written down
- Be truthful about how much they are drinking and eating
- Use the Bristol Stool Chart to document types of poo.



DAY & TIME	FIBRE AMOUNT	FLUID AMOUNT	TYPE OF POOH	MEDICATION TYPE & AMOUNT



DAY & TIME	FIBRE AMOUNT	FLUID AMOUNT	TYPE OF POOH	MEDICATION TYPE & AMOUNT



DAY & TIME	FIBRE AMOUNT	FLUID AMOUNT	TYPE OF POOH	MEDICATION TYPE & AMOUNT



DAY & TIME	FIBRE AMOUNT	FLUID AMOUNT	TYPE OF POOH	MEDICATION TYPE & AMOUNT

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