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Appendix 1: Checklist for Diagnostic workup

Inflammatory Bowel Disease – At Diagnosis Checklist

Patient Details	
Name:	
DOB:	Label
Number:	

Diagnosis	CD	UC	IBDU/IC
Location			

Baseline investigations			
PCDAI/PUCAI at diagnosis		PGA at diagnosis	
ESR		CRP	Albumin
FBC		Iron studies	B12/Folate
Liver chemistry		Ca/Mg/PO	Vitamin D
MRI/Barium FT		Stool M/C/S	Calprotectin
TPMT activity	Low	Intermediate	Normal

Vaccination/Infection Status	
Standard Schedule up to date	
Date last MMR/DPT	
HBV	VZV
Past Medical History	
TB	chronic infections Malignancy

Appendix 2: Tertiary Paediatric Gastroenterology Contact details

North Island

Paediatric Gastroenterology, Starship Children's Health

For non-urgent matters

Phone Gastro administrator (Dani Ta'ase) via switchboard (09) 307 4949 ext 5471

Fax (09) 375 4371

For urgent matters

Phone the on call Gastroenterology consultant via Switchboard

South Island

Prof Andrew Day, Christchurch Hospital

For non-urgent matters

Phone Paediatric Department, Christchurch (03) 3640730

Fax 03-3640919

Email andrew.day@otago.ac.nz

For urgent matters

Phone via hospital switchboard (03) 364 0640

Mobile 027-5913584

(As Prof Day is the only tertiary Paediatric Gastroenterologist in the South Island, during leave, the Starship Gastroenterology team will be happy to provide advice for urgent matters).

IBD Team Contact Lists

It is important that patients (and their families) know which people are contributing to their IBD management along with relevant contact details.

Following are two examples of “MY IBD TEAM” contact lists. The first example is more appropriate for children in a tertiary centre, whilst the second would be more appropriate for a regional centre. Each centre should adapt the form to their particular circumstances, and add the names of all relevant people also with contact details (phone numbers etc.).

Appendix 3a:

MY IBD TEAM

General Practitioner

Paediatric Gastroenterologist

Dietitian

Nurse

Other key people

After hour contact numbers

Other important numbers

Appendix 3b:

MY IBD TEAM

General Practitioner

Paediatrician

Paediatric Gastroenterologist

Dietitian

Nurse

Other key people

After hour contact numbers

Other important numbers:

Appendix 4: Exclusive Enteral Nutrition Protocol

Exclusive Enteral Nutrition (EEN):

EEN involves the use of a nutritionally complete liquid diet given exclusively (instead of usual food and fluids) for a defined period of time to induce remission of active Crohn's disease (CD). In contrast, the term supplementary enteral nutrition refers to the provision of a certain volume of an enteral formula in addition to standard diet.

Indications for EEN:

- ◆ Initial therapy for all children and adolescents with new diagnosis of CD, regardless of the predominant location of disease.
- ◆ Secondary therapy in children with long-standing CD who have not maintained control with standard drug therapy/therapies. In this case EEN is added to the patient's regimen in addition to the patient's other therapies.
- ◆ **NB:** EEN appears to be less efficacious in ulcerative colitis (UC) but is not contraindicated in this condition.

Initiating EEN:

- ◆ Prior to and/or after diagnosis, discuss EEN as a therapeutic option to induce remission with the patient/family. This discussion should include review of the pros and cons of EEN, and comparison of this therapy with the alternative drug regimens.
- ◆ Provide the handout **Guide to nutritional therapy for patients with Inflammatory Bowel Disease**
- ◆ Collect growth data, including accurate height and weight measurements. Review past growth patterns and plot all available parameters on an appropriate growth chart.
- ◆ Based upon the child's current age, weight and growth pattern, the child's specific fluid and caloric requirements will need to be calculated to determine the volume and type of formula required per day.
- ◆ The formula volumes given each day should be progressively increased over the first 3-4 days. This helps to prevent initial symptoms of feed intolerance, such as nausea, bloating or fullness. A standard approach involves the administration of 50% of the required volume on day one, 75% on day 2 and then full volume by day three. A plan for the ongoing administration of formula is worked out in a way that suits the child and family.
- ◆ Children with severe nutritional impairment at the time of commencing EEN may be at increased risk of developing refeeding syndrome. Slower introduction of EEN, along with appropriate monitoring, would be indicated in this setting.

Other issues during EEN:

- ◆ Emphasise that no additional food is permitted during the period of EEN. Additional water to drink is encouraged.
- ◆ Numerous practical issues can arise during the period of exclusive nutritional therapy, such as managing EEN at school. Offer practical strategies to support the child/family at home and school. Almost every conceivable issue has been encountered in the past – there are many tips and techniques to cope with and manage these.
- ◆ Some of the common issues are dealt with in the **Guide to nutritional therapy for patients with IBD**. In addition, common issues should be mentioned and discussed prior to starting EEN. Dealing with these issues as they arise is undertaken either during support calls or at times of review.
- ◆ There are essentially no side effects related to EEN. However, some children may have some initial bloating or early satiety during the first few days. Avoiding supplements or adjunct agents, such as iron, during the initial stages can be helpful. A brief period of acid suppression can help with resolution of these symptoms and assist the initial tolerance of the formula. Often times, children have slightly semi-formed motions whilst on EEN.
- ◆ Children may report a white coating on the surface of their tongue. Although thrush may need to be excluded, this generally resolves with good oral hygiene. Children should maintain regular dental hygiene during EEN, with brushing of teeth and tongue 2-3 times daily and use of an age-appropriate mouth wash. In addition to providing a chewing action, the prudent use of sugar-free gum helps to stimulate saliva production.

EEN Formula:

- ◆ Polymeric (intact protein) formulae are preferred over elemental formulae, as they have better taste acceptance. Similar efficacy is seen with either formulae.
- ◆ Most children are able to take a polymeric formula orally: occasionally a nasogastric tube is required for part or all of duration of the EEN period.
- ◆ Various formulae can be used. Children should have the opportunity to taste the various options to assess which they prefer.
- ◆ After establishing the appropriate formula for each child, a special authority number will need to be obtained. The formula requirements can then be provided on a script. Parents will be able to obtain supplies from their local community pharmacy or home delivery service. Provision of a small initial supply of formula is encouraged.

Ongoing review and follow-up during period of EEN:

- ◆ EEN is usually recommended for an eight week period. Shorter periods may be indicated in certain circumstances, such as in the management of a disease exacerbation subsequent to diagnosis.
- ◆ Close multi-disciplinary team support during EEN is essential to ensure that compliance is maintained throughout the length of the nutritional therapy, and to optimise the success of the therapy. Close day to day support should be provided by phone or email contact with members of the team, on an as necessary basis.
- ◆ Regular multi-disciplinary review should be undertaken during the period of EEN. A standard frequency involves review every two weeks: however in some circumstances review will be required more frequently. At review visits compliance with feeds will be assessed, any difficulties with the regimen managed, growth reviewed, general progress assessed and volumes adjusted accordingly. Inflammatory markers may be measured at regular intervals during the period of EEN to monitor the response to therapy.
- ◆ In addition to support provided by the treating team, peer support may be appropriate and can be arranged on an individual basis. Usually this involves identifying a child of a similar age, and/or from a similar area geographically, who is then able to make contact (email/phone/direct) with the child who is just starting on EEN. Although not all children are comfortable with this initially, it should be always offered or mentioned.

Completion of EEN and recommencement of normal diet

- ◆ Prior to the completion of the prescribed period of EEN, it is important to start discussing and planning the reintroduction of normal diet. The best accepted manner in which to do this is the reintroduction of one small meal per day for 3 days, followed by a second meal and so on. During this period the volume of enteral formula is slowly reduced. [See Appendix 5: **Reintroducing food after exclusive enteral nutrition therapy**].
- ◆ There is no evidence to support the gradual introduction of one food at a time, or for the introduction of fluids before solids following a period of EEN. The former method often becomes very confusing for parents and the child because it introduces a fear associated with particular foods in their ongoing diet. It is very uncommon for a child with CD to have difficulties associated with the reintroduction of particular types of foods.
- ◆ Following the re-introduction of normal foods, ongoing supplementary enteral nutrition is encouraged. Maintenance of a small ongoing volume (e.g. 500-750 mls daily) may be sufficient to maintain remission.
- ◆ Many children will commence maintenance medical drug therapy prior to or at the completion of EEN.

Guide to Nutritional Therapy for Patients with Inflammatory Bowel Disease (IBD)

Why has nutritional therapy been suggested?

Nutritional therapy is a change of diet which may help get your bowel disease under control. It can also help to improve your growth. Many children and teenagers have used this therapy around the world with great success. The change in diet works to undo the changes in the lining of the bowel. This helps to improve symptoms, such as abdominal pain and diarrhoea. Often the therapy is used without other medicines being needed. Sometime it may be used in combination with other medicines.

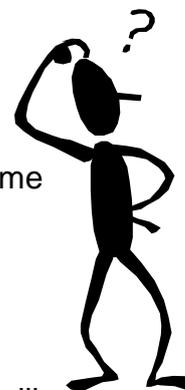
What does nutritional therapy involve?

Nutritional therapy involves drinking a special milk type drink instead of eating food. These drinks are often called formula.

The name of your formula is _____. This formula provides all of the energy, vitamins and minerals that your body needs. It replaces what you would usually get from food. It looks like milk and tastes slightly sweet like a milkshake.

How much will I need to drink?

You are required to drink _____ mls of formula per day to meet your body's requirements and to help you reach a healthy weight. Depending on weight gain this volume may need to increase. If this volume does not satisfy your appetite, you can drink more.



Should I drink this amount on the first day?

No! Your body should get used to the volume of fluid slowly. Your dietitian will work with you to decide how much to drink on the first few days. By the third or fourth day you should be drinking the full amount.

How long will I be doing this for? Your Doctor will tell you exactly how long, but usually the best results are seen after 6-8 weeks on the diet.

When should I drink? Your dietitian will discuss a daily drinking routine with you and your family. How much and how often you drink is very individual. It is best to split the volume up into 6 – 10 drinks per day to satisfy your appetite. Some people

like to take small sips every hour or every 2 hours. School and other activities in your life must be considered when designing a plan.

For example, if you needed to drink 1800mls per day: You could have 300mls, 6 times per day: at breakfast, morning tea, lunch, afternoon tea, dinner and supper OR you may choose to drink 180mls, 10 times per day.

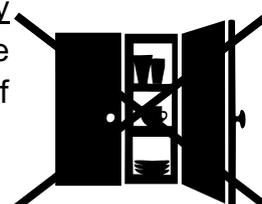
What if I can't drink it all? If you find the amount is too much for you to drink or that this diet is becoming too hard for you, we can help you. We can put a tube in your nose that goes into your stomach. This is called a naso-gastric tube. Some of your formula can be given during the night through this tube. This means that you only need to drink what is comfortable during the day. With lots of support from family and the IBD team, we will help you through the difficult early stages.

What will I do at meal times? Family meal times can be hard when everybody else is eating except for you. We suggest to families that that they are very supportive around this time. They can do things like not discussing food and eating in another room. Some families don't cook their child's favourite meal until they are able to eat again. This way the family is also missing out on something and can understand what their child is going through. Some people are very happy to sit at the table and drink while their family eats. It does get easier after the first few weeks.



Can I still go to school? Yes you can. Provided you have the energy, you should be able to continue with your normal daily activities. School, sport, hobbies, helping around the house and activities with friends should happen during this time. Parents should talk to your school year adviser or classroom teacher about your nutritional therapy. It needs to be treated with the same importance as taking medicine. The formula should be kept cold. Take it in a cooler bag to school, or arrange for it to be stored in a fridge (usually the staff room of a favourite teacher). Some people take sips during class, others manage well at meal breaks only. You may like to tell your friends about your nutritional therapy so they will understand why you can't eat for 6-8 weeks.

What else will I be able to eat or drink? Several studies have shown that this treatment works the best when given by itself, without ordinary food. Even having a small amount of ordinary food along with the formula may mean that it does not work as well. Because of these studies, we do not allow you to eat any food whilst following this treatment. You can drink water, but be aware that if you fill up on too much water, there won't be a lot of room for your formula!



Some children and teenagers find they miss out on chewing. It's OK to have some sugar free gum when really needed. Be careful not to go 'overboard' with the sugar free gum though. The artificial sweeteners can cause diarrhoea.

Can I add anything to my drink? For the same reason as explained above, it is ideal that you drink the formula only. Adding ice keeps your drink chilled which often tastes better than having it at room temperature. You may prefer to drink through a straw or from a sports drink bottle. Bottles make travelling and school easier.

Will there be any side effects? We expect these feeds will settle down your bowel symptoms. We would also expect your energy levels and weight will improve. You may find that while you are having this diet that your bowel movements are softer than usual. This is mainly because you are having a completely liquid diet. Some children and teenagers report feeling full in the beginning, but this improves as your body gets used to having the formula. We don't expect that you will have any other side effects related to the therapy.

What else do I need to know? Please speak with your Gastroenterologist or dietitian if you have further questions. You can write the answers below.

Answers to questions:

My drinking plan:

(your Dietitian will help you with this)

Appendix 5B: EEN Handout - Guide for Parents

Guide to Nutritional Therapy for Patients with Inflammatory Bowel Disease (IBD) *Guide for Parents*

Why has nutritional therapy been suggested?

Nutritional therapy is a change of diet which may help get your child's bowel disease under control. It can also help to improve your child's growth. Many children and teenagers have used this therapy around the world with great success. The change in diet works to undo the changes in the lining of the bowel. This helps to improve symptoms, such as abdominal pain and diarrhoea. Often the therapy is used without other medicines being needed. Sometime it may be used in combination with other medicines.

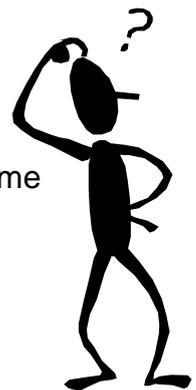
What does nutritional therapy involve?

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The name of your child's formula is _____. This formula provides all of the energy, vitamins and minerals that your child's body needs. It replaces what he/she would usually get from food. It looks like milk and tastes slightly sweet like a milkshake.

How much will your child need to drink?

Your child will be required to drink _____ mls of formula per day to meet their body's requirements and to help reach a healthy weight. This volume may need to increase depending on weight gain. If this volume does not satisfy your child's appetite, he/she can drink more.



Should my child drink this amount on the first day?

No! Your child's should get used to the volume of fluid slowly. Your dietitian will work out how much for your child to drink on the first few days. By the third or fourth day they should be drinking the full amount.

How long will my child be doing this for? Your Doctor will tell you exactly how long, but usually the best results are seen after 6-8 weeks on the diet.

When should my child drink? Your dietitian will discuss a daily drinking routine with your child. How much and how often they drink is very individual. Often it is best to split the volume up into 6 – 10 drinks per day to satisfy your child's appetite. Some children like to take small sips every hour or every 2 hours. School and other activities in your child's life must be considered when designing a plan.

For example, if your child needed to drink 1800mls per day: they could have 300mls, 6 times per day: at breakfast, morning tea, lunch, afternoon tea, dinner and supper OR they may choose to drink 180mls, 10 times per day.

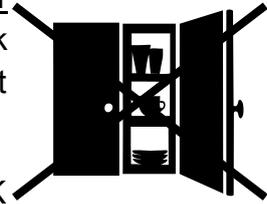
What if my child can't drink it all? If your child finds the amount is too much to drink or that this diet is becoming too hard for them, we can help you. We can put a tube in your child's nose that goes into their stomach. This is called a naso-gastric tube. Some of your child's formula can be given during the night through this tube. This means that they only need to drink what is comfortable during the day. With lots of support from family and the IBD team, we will help you and your child through the difficult early stages.

What will my child do at meal times? Family meal times can be hard when everybody else is eating except for the person having this liquid diet. We suggest to families that that they are very supportive around this time. They can do things like not discussing food and eating in another room. Some families don't cook their child's favourite meal until they are able to eat again. This way the family is also missing out on something and can understand what their child is going through. Some children are very happy to sit at the table and drink while their family eats. It does get easier after the first few weeks.



Can my child still go to school? Yes, they can. Provided they have the energy, your child should be able to continue with normal daily activities. School, sport, hobbies, helping around the house and activities with friends should happen during this time. You should talk to your child's school year adviser or classroom teacher about their nutritional therapy. It needs to be treated with the same importance as taking medicine. The formula should be kept cold. Your child can take it to school in a cooler bag, or arrange for it to be stored in a fridge (usually the staff room of a favourite teacher). Some children take sips during class, others manage well at meal breaks only. Your child may like to tell their friends about their nutritional therapy so they will understand why your child can't eat for this time.

What else will my child be able to eat or drink? Several studies have shown that this treatment works the best when given by itself, without ordinary food. Even having a small amount of ordinary food along with the formula may mean that it does not work as well. Because of these studies, we do not allow your child to eat any food whilst following this treatment. They can drink water, but be aware that if they fill up on too much water, there won't be a lot of room for the formula!



Some children and teenagers find they miss out on chewing. It's OK to have some sugar free gum when really needed. Be careful not to go 'overboard' with the sugar free gum though. The artificial sweeteners can cause diarrhoea.

Can I add anything to my child's drink? For the same reason as explained above, it is ideal that they drink the formula only. Adding ice keeps their drink chilled which often tastes better than having it at room temperature. They may prefer to drink through a straw or from a sports drink bottle. Bottles make travelling and school easier.

Will there be any side effects? We expect these feeds will settle down your child's bowel symptoms (such as pain). We would also expect your child's energy levels and weight will improve. You may find that while your child is having this diet that their bowel movements are softer than usual. This is mainly because they are having a completely liquid diet. Some children and teenagers report feeling full in the beginning, but this improves as their body gets used to having the formula. We don't expect that your child will have any other side effects related to the therapy.

What else do I need to know? Please speak with your Gastroenterologist or dietitian if you have further questions. You can write the answers below.

Answers to questions:

My child's drinking plan:

(your Dietitian will help you with this)

Appendix 6: Reintroduction of Standard Diet after EEN Handout

Reintroducing Food after Exclusive Enteral Nutrition Therapy

After drinking the specialised formula up to 8 weeks, your body should be slowly reintroduced to food again. There is no known food that may cause symptoms or a 'flare' for people with Crohn's disease, but there may be a particular food that does not agree with you.

To slowly get back into the habit of eating, you will reintroduce one meal at a time and slowly build up to your usual eating pattern of regular meals and snacks.

The first foods eaten should be fairly plain and low in fibre. Refer to the first foods (stage 1) section for more detail. Gradually more rich, fatty and spicy foods will be introduced when your diet is more varied.

How much you eat at the first few meals will depend on your appetite and the amount of specialised formula the doctor/dietitian want you to drink while you gradually introduce food again. Therefore each eating plan will be slightly different for individual patients. Your dietitian will tailor the eating plan to your specific needs and requirements.

Enjoy eating again!!!!



Steps to introducing food after your liquid diet

Step 1

Choose a meal (doesn't have to be the same meal each day). Select foods from the First foods (Stage 1) list. Use a small plate the first time but aim for a "normal" sized meal as soon as you can.

Continue to have _____mls/packets of supplement drink per day

Continue this for 3 days, watching for any IBD symptoms

Step 2

Have two meals a day (doesn't have to be the same meals each day). Select foods from the First foods (stage 1) list. Aim for normal sized meals.

Continue to have _____mls/packets of supplement drink per day

Continue this for 3 days, watching for any IBD symptoms

Step 3

Have three meals a day. Select foods from the First foods (stage 1) list. Aim for normal sized meals.

Continue to have _____mls/packets of supplement drink per day

Continue this for 3 days, watching for any IBD symptoms

Step 4

Have three meals a day and add in some snacks. Select foods from the Next Step (Stage 2) list. Aim for normal sized meals.

Continue to have _____mls/packets of supplement drink per day

Continue this for 3 days, watching for any IBD symptoms

If you experience any return of IBD symptoms return to Step 3

Step 5

Continue to eat three meals and snack regularly.

Take _____mls/packets of supplement drinks per day

Try foods from the Try Last (Stage 3) list, you don't have to eat all of them, pick the ones you have missed the most

Some first meal ideas

Pita pizza – pita bread, tomato puree, shaved ham or cooked mince and cheese

Tuna pasta – pasta, tuna tinned in water, white sauce, bread crumbs and cheese

Roast dinner – remove the skin and fatty bits, no stuffing

Chicken nuggets or fish “fingers” – use homemade white bread crumbs or a light tempura style batter, shallow fry

Sandwiches or toast – white or fine wholemeal bread, margarine and fillings (cheese, smooth peanut butter, seedless jams or honey)

Rice bubbles – with milk and smooth yoghurt

Eggs – scrambled, as an omelette, with white or fine wholemeal bread.

Please contact your dietitian _____ with any questions or concerns on
_____ .

Food groups	First foods (Stage 1)	Next step (Stage 2)	Try last (Stage 3)
Bread	White bread, flat bread, pita, rolls or toast, plain English muffins Fine wholemeal bread	Coarse wholemeal bread Wholemeal pita or flat breads	Very fresh bread Wholegrain bread Bread containing dried fruit, whole grains, nuts or seeds
Cereals	Cornflakes, puffed rice White flour, cornflour Pasta or white rice	Porridge, Weet-bix Wholemeal flour Brown rice, couscous	Muesli Bran cereals
Biscuits and cakes	Biscuits, cake, crackers, muffins, pancakes, pikelets, scones or sponge made without coconut, dried fruit, grains, seeds or nuts		Snack bars, biscuits, cake, crackers, muffins and scones containing coconut, dried fruit, grains, seeds or nuts
Fruit	Raw, cooked or tinned, without pips, seeds or skins Fruit juice without pulp Jams or marmalades without seeds or pith	Tinned pineapple	Berries, citrus fruit, fresh pineapple Dried fruit e.g. dates, sultanas and apricots Fruit juice with pulp
Vegetables	Tender vegetables – peeled and cooked e.g. carrot, kumara, parsnip, potato, pumpkin and yam Pureed or creamed vegetable soup Tomato paste or puree	Dahl (not spicy), pureed lentils, hummus Broccoli or cauliflower tops Cabbage, lettuce or silverbeet leaves (no stalks) Courgettes/marrow without skin or seeds, green beans, raw carrots Creamed corn Whole tinned tomatoes with seeds removed	Vegetables with coarse stalks, pips, seeds and skins e.g. corn (including popcorn) cucumber, garlic, onion, peas, raw tomato Baked beans, whole beans and lentils Coleslaw Pickle, relish Chopped chilli, garlic and ginger. Fresh herbs

Food groups	First foods (Stage 1)	Next step (Stage 2)	Try last (Stage 3)
Meat, fish, poultry and eggs	Lean chicken, fish, lamb or minced beef Fish tinned in water Eggs Smooth pate or spread	Pork Skinless sausages Roast meat, steak	Tough gristly or fatty meat Chicken skin Sausage skins
Milk products and cheese	Milk, cheese, cottage cheese, cream cheese, sour cream Plain yoghurt, dairy food	Fruit yoghurt (no seeds)	Cheese with seeds or nuts Yoghurt with bits
Nuts and seeds	Smooth peanut butter	Finely ground nuts Tahini	Pumpkin sesame or sunflower seeds Nuts – whole or chopped Crunchy peanut butter
Dessert	Milk puddings, ice cream, jelly, plain yoghurt		Puddings containing coconut, dried fruit, nuts, pips, seeds and skins
Miscellaneous	Oil, margarine, butter Tomato sauce, soya sauce, gravies Mayonnaise Smooth salad dressings Chocolate (remember it's a treat)	Deep fried foods (except those in Stage 3)	Chunky sauces (ie satay), sauces with chilli flakes (ie chilli sauce) Vinaigrette

Appendix 7: Pharmacopoeia

Pharmacopoeia for Paediatric IBD

Prednisone	2 mg/kg/day (max 40-50 mg /day) in the morning (for initial period, then reduce as appropriate)
Budesonide	6-9 mg/day initially, then reduce
IV Steroids	Methylprednisolone 1 mg/kg/day (q12h) to max of 60 mgs daily Hydrocortisone 2-4 mg/kg/day (q6h)
Sulphasalazine	50-75 mg/kg/day (up to 3-4 grams daily)
5-ASA	30-50 mg/kg/day (maintenance)
Metronidazole	10 mg/kg/dose BD (max 800 mg daily)
Ciprofloxacin	10 mg/kg/dose BD (max 1000 mg daily)
Azathioprine	Start 1 – 1.5 mg/kg/day - Increase to approx 2.5 mg/kg/day (max 200 mgs/day) **
6-MP	Start 1 mg/kg/day - Increase to approx 1.5 mg/kg/day **
Methotrexate	10 mg/m ² initially, then 15 mg/m ² (max 25 mg) weekly sc **
Tacrolimus	Commence at 0.1 mg/kg/day in 2 divided doses p.o. ** Usual dose 0.2 mg/kg/day in 2 divided doses p.o. (ongoing dose dependant on levels)
Cyclosporin	3-8 mg/kg/dose Q12H
Mycophenylate (MMF)	15 mg/kg/day

** see individual protocols

Available Preparations

Budesonide	3 mg tab (90)
Prednisone	1 mg, 2.5 mg, 5 mg, 20 mg tab
SSZ	500 mg tab - EN (100)
Asacol	400 mg tab (100) 500 mg suppos (20)
Pentasa	500 mg tab (100) 1 g suppos (28), 1 g enema (7), 1 g granules
Olsalazine	250 mg cap/500 mg tab
Metronidazole	200 mg, 400 mg, 200/5mls (100ml), 1g suppos
Ciprofloxacin	250 mg (30), 500 mg (30), 250mg/5ml (100ml), 500mg/5ml (100 ml)
Azathioprine	50 mg (100)
6-Mercaptopurine	50 mg
Methotrexate	20 mg/2ml
Tacrolimus	0.5 mg, 1 mg, 5 mg

Appendix 8: Using Sulphasalazine and 5-Aminosalicylates

Sulphasalazine and 5-ASA Guideline

Checklist before commencing Sulphasalazine/5-ASA

- (1) Review any history of Sulpha allergy (patient or family): Sulphasalazine then contraindicated if allergic history
- (2) Review current medications
- (3) Review side-effects profile
- (4) Give Information Sheet

Baseline Tests

- (1) Full blood count
- (2) Liver chemistry

Dosage schedule

Standard dose 50 mg/kg/day, given in 2-3 divided doses

Dosage increased progressively over 7-10 days

- (1) Commence at 25% of final dose
- (2) Increase after 3 days to 50% of final dose
- (3) Increase after a further 3 days to 75% of final dose
- (4) Increase after 3 days to final (full) dose

Monitoring

- (1) FBC, renal function and liver function tests
- (2) Monitor renal chemistry at least every 12 months

Appendix 9: Using Thiopurines

Thiopurines in IBD: Guideline

Checklist before commencing Azathioprine

- Review past immunosuppressive therapy
- Review current immunosuppressive therapy
- Review side-effects profile
- Give Information Sheet
- Check patient's weight
- Check TPMT level

Baseline Tests

- Full blood count
- Liver chemistry

Dosage schedule

- Azathioprine given once daily in morning
- Starting dosage in TPMT sufficient: 12.5 mg (if < 25 kg), 25 mg (25-50 kg) or 50 mg (>50 kg)
- After review of 2 sets of blood results, increase dose to 2.0 - 2.5 mg/kg/day (max dose of 200mg/day)
- Consider readjusting dose for growth over time
- If TPMT level in heterozygote range, commence Azathioprine at half the above dose
- If TPMT level suggestive of homozygous deficiency, avoid azathioprine/6MP

Monitoring

- FBC and Transaminases
- After 1, 2, 4, 8, and 12 weeks of starting Azathioprine

Every three months there-after

Bloods locally or at Paediatrics

If done locally, request that results faxed urgently

Ensure results reviewed

6MMP and TGN

Measure after at least 8 weeks on full dose

Re-measure 4 weeks after any subsequent dose change

Consider repeating every 12 months

Consider measuring if concerns about compliance

Aim for TGN > 235 for efficacy

High TGN levels may be associated with myelosuppression

High 6MMP levels may be associated with hepatotoxicity

Amylase and Lipase

Routine measurement NOT indicated

Only measure if concerns of possible pancreatitis

NOTE: 6-MP may sometimes used instead of Azathioprine. When using 6MP, a similar regimen can be followed, except that the usual expected dose of 6-MP is 1.5 mg/kg/day (with daily doses about half of that for Azathioprine).

Thiopurine Checklist

Patient Sticker here

Initiation of Azathioprine/6-MP

Weight: _____

TPMT level: _____

Initial Dosage: _____

Subsequent dosage: _____

Monitoring:

	Date	Results viewed	Action required
Week 1:			
Week 2:			
Week 4:			
Week 8:			
Week 12:			

Notes:

Appendix 10: Using Methotrexate

Methotrexate Guideline

Name:

NHI: (sticker here)

DOB:

Checklist before commencing Methotrexate:

1. Review vaccination history: catch up if necessary
2. Review past immunosuppressive therapy
3. Review current immunosuppressive therapy
4. Review side-effects profile

Baseline tests:

1. Weight: _____ Height: _____
2. Calculate body surface area (BSA): _____
(BSA (m²) = sqrt (Wt(kg) x Ht (cm)) / 3600) or via online calculator
3. Full blood count
4. Liver chemistry tests (Consider liver ultrasound +/- further investigation if abnormal chemistry)
5. Serum creatinine
6. Chest X-ray if necessary

Dosage schedule:

1. Dosing based upon BSA
2. Incremental dosing as per below table:

Week	Dosing
1	10 mg/m ² = 10 x BSA =
2	10 mg/m ² =
3	15 mg/m ² =
Onwards	(maximum weekly dose is 25 mg)

Folic acid supplementation:

Folic acid supplements are required to avoid folic acid deficiency. Supplementation may also reduce nausea related to methotrexate. Folic acid should not be given on the day of injection.

Standard dose: 5 mgs given two days following each injection.

Monitoring:

1. Full blood count , liver function test and serum creatinine:
 - Weeks 1, 2, 4, 8 and 12 after starting Methotrexate.
Review results prior to giving the injection.
 - Every 3 months thereafter.

2. Review BSA on annual basis and adjust dose as required.

Methotrexate Checklist

Patient Sticker here

Initiation of Methotrexate

Weight: _____

BSA: _____

Initial Dosage: _____

Subsequent dosage: _____

Monitoring:

	Date	Results viewed	Action required
Week 1:			
Week 2:			
Week 4:			
Week 8:			
Week 12:			

Notes:

Appendix 11: PUCAI Score

Paediatric Ulcerative Colitis Activity Index: PUCAI

ITEM	POINTS
1. Abdominal pain	
No pain	0
Pain can be ignored	5
Pain cannot be ignored	10
2. Rectal bleeding	
None	0
Small amount only, in less than 50% of stools	10
Small amount with most stools	20
Large amount (>50% of the stool content)	30
3. Stool consistency of most stools	
Formed	0
Partially formed	5
Completely unformed	10
4. Number of stools per 24 hours	
0-2	0
3-5	5
6-8	10
>8	15
5. Nocturnal stools (any episode causing wakening)	
No	0
Yes	10
6. Activity level	
No limitation of activity	0
Occasional limitation of activity	5
Severely restricted activity	10
SUM OF PUCAI (0-85)	

Appendix 12: PCDAI Score

Paediatric Crohn's Disease Activity Index: PCDAI

Abdominal pain

None	0
Mild (brief episodes, not interfering with activities)	5
Moderate/severe (frequent or persistent, affecting with activities)	10

Stools

0-1 liquid stools, no blood	0
2-5 liquid or up to 2 semi-formed with small blood	5
Gross bleeding, >6 liquid stools or nocturnal diarrhoea	10

Patient functioning, general well-being (Recall, 1 week)

No limitation of activities, well	0
Occasional difficulties in maintaining age appropriate activities, below par	5
Frequent limitation of activities, very poor	10

EXAMINATION

Weight

Weight gain or voluntary weight loss	0
Involuntary weight loss 1-9%	5
Weight loss >10%	10

Height

< 1 channel decrease (or height velocity > -SD)	0
> 1<2 channel decrease (or height velocity < -1SD> -2SD)	5
> 2 channel decrease (or height velocity < -2SD)	10

Abdomen

No tenderness, no mass	0
Tenderness, or mass without tenderness	5
Tenderness, involuntary guarding, definite mass	10

Peri-rectal disease

None, asymptomatic tags	0
1-2 indolent fistula, scant drainage, tenderness of abscess	5
Active fistula, drainage, tenderness or abscess	10

Extra-intestinal manifestations

Fever > 38.5 x 3 days in week, arthritis, uveitis, erythema nodosum, or pyoderma gangrenosum

None	0
One	5
Two	10

LABORATORY

Hct (%)

<u>< 10yrs</u>	<u>11-14 (male)</u>	<u>11-19 (female)</u>	<u>15-19 (male)</u>	
> 33	> 35	> 34	> 37	0
28-33	30-34	29-33	32-36	2.5
< 28	< 30	< 29	< 32	5

ESR (mm/hr)

< 20	0	<u>Albumin (g/L)</u>	> 35	0
20-50	2.5		31-34	5
> 50	5		< 30	10

TOTAL =

Appendix 13: Annual Review

IBD Clinic Annual Review Checklist

Blood tests

- FBC
- ESR, CRP
- Liver chemistry
- Renal function
- Vit D, Ca, Mg, PO
- Iron, B12, Folate

- Growth
- Dietitian review
- Immunisation status

When indicated only:

- Thiopurine metabolites
- Faecal Calprotectin
- Pubertal status
- Bone mineral density scan
- Bone age
- Psychologist review
- Social work review
- Transition planning
- Knowledge review

Appendix 14: Internet Resources

IBD Resources on the Web

Specific sites for children and young people:

www.ucandcrohns.org

www.kidsibd.org

<http://www.ibdu.org/> (site for older teens/young adults)

<http://www.pedsibd.org/teens/index.html>

National organizations:

New Zealand (CCNZ) <http://crohnsandcolitis.org.nz/>

Australia (ACCA) www.acca.net.au

USA (CCFA) www.ccfa.org

UK (NACC) www.nacc.org.uk/content/home.asp

Canada (CCFC) <http://www.ccfc.ca/>

(English and French sites, Various brochures available)

Other Resources

NASPGHAN

www.naspghan.org/index.cfm (Family Resources)

<http://www.naspghan.org/wmspage.cfm?parm1=354>

(Info sheets about CD, Nutrition and UC: in English, French, Portuguese and Spanish)

<http://www.reachoutforyouth.org/>