The Winston Churchill Memorial Trust of Australia

Report by Sharon Lamb – 2008 Churchill Fellow

The Nutritional Management of Short Bowel Syndrome

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Signed: ___________________________ Dated: 26/11/08
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Introduction

Short Bowel Syndrome (or more broadly termed Intestinal Failure) refers to a "reduced intestinal absorption so that macronutrient and/or water and electrolyte supplements are needed to maintain health and/or growth". This is most commonly due to major intestinal surgery that leaves inadequate small bowel for normal function, most commonly the result of Crohn's disease, hereditary polyposis, tumours or catastrophic resections. Intestinal Failure can also result from inadequate bowel function, as opposed to a shortened length of bowel, and includes people suffering radiation enteritis or myopathy.

Intestinal Failure is life threatening if untreated or mistreated. It is an extremely complex syndrome requiring expert medical management, and patients often require long term parenteral nutrition. As Australia currently does not have a specialist centre for the management of Intestinal Failure, this travel programme aimed to visit National Intestinal Failure centres in the United Kingdom and the United States of America, and to learn more about advanced nutrition support and the most current research in the area.

In funding such an extensive visit I would like to sincerely thank the Churchill Trust for deeming this a worthwhile project. For supporting this travel and allowing extended leave from work, I would also like to thank Sydney South West Area Health Service (SSWAHS) and namely Dr Jennifer Ravens, Area Director of Nutrition and Dietetics (EZ) and Dr David Storey, Head of Upper Gastrointestinal Surgery, RPAH.

In being able to visit these centres I was able to gain extensive insight into the medical, surgical and nutritional management of this group of patients, and for this I would like to sincerely thank the following people:

- Dr Jeremy Nightingale and Alison Culkin (Senior Intestinal Failure Dietitian)
  St Marks Hospital, Harrow, London, UK
- Kirstine Farrer, Consultant Dietitian
  Hope Hospital, Salford, Manchester, UK
- Professor Alan Buchman
  Northwestern University Hospital, Chicago, USA
- Carol Parrish and Joe Krenitsky, Senior Medical Nutrition Support Dietitians
  University of Virginia Hospital, Charlottesville, USA
- Neha Parekh, Intestinal Rehabilitation Programme Lead Dietitian
  Cleveland Clinic, Ohio, USA

Executive Summary - The Nutritional Management of Intestinal Failure

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The Churchill fellowship has allowed me to travel to centres of excellence in managing intestinal failure. In being able to do this I have been able to work with world-renown specialists and have gained extensive knowledge in the nutritional management of this group of patients. Of particular importance were the two national intestinal failure units in England. The intestinal failure specialist Dietitians at St Marks Hospital and the Hope Hospital were inspirational.

Nutritional input is vital when managing these patients and requires expert parenteral, enteral and oral intake advice. Careful management of food and fluid through dietary change and pharmacology can improve absorption and help with fluid and electrolyte balance. This in turn can minimize the need for parenteral nutrition. Fistuloclysis is also a novel but successful way to manage intestinal failure for some patients.

Whilst the sites visited consist of large multidisciplinary teams, the aim in returning to Australia is to make my nutritional skills and knowledge available to patients and other health professionals to improve patient care here. This will be done by being involved in clinical updates through national nutrition societies, and also to develop a nutrition clinic for patients.
Fellowship Programme

13th – 16th September – European Society for Parenteral and Enteral Nutrition (ESPEN) conference
Florence, Italy
- Intestinal Failure Workshop
- Surgical aspects of Small Bowel Transplantation

22nd – 26th September – St Marks Hospital, London
- Multi-disciplinary Intestinal Failure Unit (inpatient and outpatient)
- Medically focused ward rounds and Psycho-social meetings

29th September – 3rd October – Hope Hospital, Manchester
- Multi-disciplinary Intestinal Failure Unit (inpatient and outpatient)
- Surgically focused ward rounds
- Fistuloclysis

6th – 10th October – Northwestern University Hospital, Chicago
- Inpatient parenteral nutrition team
- Outpatient Intestinal Failure and Inflammatory Bowel Unit

13th – 17th October – Advanced Nutrition Support Program
University Hospital of Virginia, Charlottesville, USA
- In-depth look at fluid and electrolyte balance
- Enteral nutrition, including fistuloclysis

20th – 24th October – Cleveland Clinic, Ohio, USA
- Recently started small bowel transplantation unit.
- Inpatient nutrition support team
- Multi-disciplinary Intestinal Failure Unit (outpatient focused)
The Intestinal Failure Unit – what is required?

Each of the centres that were visited had originated as a centre of excellence by a different path. All had started with a small number of patient referrals and now were considered world-leaders in the treatment of intestinal failure.

For such an extensive unit to function, the following are essential:

Both medical and surgical expertise and support in managing intestinal failure. It does not appear to matter which specialty takes the lead in this area, but both are needed for thorough recognition and management of the complex syndrome. Surgical expertise is essential in knowing when further operations will be required. All sites visited waited a minimum of 6 months to re-operate on an intestinal failure patient in the presence of fistula/stoma, assuming the patient was stable on parenteral, enteral or oral nutrition and free from sepsis.

Strong nursing support – in the ward setting for strict parenteral line care; fluid and weight records; and wound, stoma and fistula care. This is regardless of whether there are dedicated beds for intestinal failure patients. Also the Nutrition Specialist nurse is pivotal in liaising between ward, patient and team. The nutrition nurse has a level of expertise in parenteral nutrition, enteral nutrition and stoma/fistula care.

Allied Health support – the dietitian and pharmacist are key members of the team. The pharmacist has an extensive knowledge of medications to aid fluid balance control, dosages required and absorption sites. The dietitian manages oral and enteral nutrition, closely monitors fluid balance and fluid restrictions, monitors anthropometry and liaises with food services. Both manage parenteral nutrition.

Psychological/Social Support – Although variable, access to a social worker and/or psychologist is essential. Of particular note was the inclusion of an intestinal failure psychiatrist at St Marks Hospital, London. Intuitive to the issues of this group of patients (who can often be young in age and often have had major trauma leading to the intestinal failure) the psychiatrist could invest more intensive counselling time with these patients on an ongoing basis.

Administrative Support – for large centres an administrative coordinator was vital to screen and direct all patient calls; and prioritise referrals. They also manage outcome data, source funding for patient equipment and parenteral costs.

BUT IN THE BEGINNING...

On talking with the founder of the Cleveland Clinic Intestinal Rehabilitation Program, Dr E Steiger, he informed me that the program started with a simple proposal consisting of 1 FTE Dietitian and 0.5 FTE Administrative support, with the support of medical and surgical executive. The unit has since expanded greatly and this year commenced small bowel transplantation.
The Nutritional Management of Intestinal Failure

**Oral Rehydration Solution and Fluid Restriction** – due to large fluid losses it is essential to restrict hypotonic fluid intake, which will only increase fluid losses due to the osmotic gradient of the gut. This is the most common mistake made by health professionals, in which they encourage this type of patient to drink more fluids. The only fluids that will help prevent fluid shifts and improve absorption is an oral rehydration solution with a sodium concentration of 90-120mmol and small amounts of bicarbonate and glucose. Strict fluid restrictions were used in all sites.

**Pharmacology** – ensuring protein pump inhibitors are used effectively (testing acid-base levels of effluent), high doses of Imodium (up to 60mg/day) and regular use of codeine phosphate in standard dosages.

**High Energy Diet** – Whenever possible patients should be encouraged to eat large amounts of food to maximise absorption of oral intake, even when bowel length is minimal. This was only contraindicated when there was bowel obstruction, active disease, or myopathy. The oral diet is low fibre, lower fat and higher carbohydrate (dependent on presence of colon in continuity), dry, high sodium, and lower in simple sugars.

The promotion of oral diet while on parenteral nutrition, even when patients can only take small amounts with minimal nutritional benefit was promoted to aid social wellbeing and reduce the risk of cholestasis related complications.

**Monitoring - short term**

- Weight
- Detailed fluid balance
- Biochemistry including daily electrolytes and urinary Sodium

**Monitoring - Long term**

- Weight, mid arm muscle circumference and mass, grip strength
- Detailed fluid balance
- Biochemistry – including electrolytes, key trace elements (iron) and vitamins
- Vitamin D and DEXA
# Summary of Sites visited:

<table>
<thead>
<tr>
<th></th>
<th>Cleveland Clinic, Cleveland</th>
<th>Hope Hospital, Manchester</th>
<th>Northwestern Hospital, Chicago</th>
<th>St Marks Hospital, London</th>
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</thead>
<tbody>
<tr>
<td><strong>Type of Intestinal Rehabilitation Program</strong></td>
<td>Predominantly outpatient. Commenced Intestinal Transplantation 2008</td>
<td>16 bed inpatient ward (nursing staff:patient ratio approximately 1:3), and outpatient clinics</td>
<td>Outpatient clinics No specific inpatient bed funding</td>
<td>14 bed inpatient ward plus 6 surgical beds (nursing staff:patient ratio approximately 1:3), and outpatient clinics</td>
</tr>
<tr>
<td><strong>Physician lead</strong></td>
<td>Surgical and gastroenterologist led.</td>
<td>Surgical led (although head of service gastroenterologist)</td>
<td>Gastroenterologist led with surgical input</td>
<td>Gastroenterologist led, with surgical input</td>
</tr>
<tr>
<td><strong>Dietitians</strong></td>
<td>2.5 FTE clinical 0.5 FTE management</td>
<td>1 FTE clinical and management</td>
<td>Transplant Dietitian to consult in clinics (max 0.2 FTE)</td>
<td>Approx 2 FTE clinical 0.5 FTE research</td>
</tr>
<tr>
<td><strong>Other Lead Team Members</strong></td>
<td>Nutrition Support Team (7 Dietitians and 2 Vascular Access/ Nutrition Nurses, Social Worker) Physician Assistant Secretarial Support</td>
<td>Intestinal Failure Coordinator Home PN nurse Lead inpatient nurse manager and nursing staff Pharmacist Psychologist</td>
<td>PN team (2 nurse consultants; pharmacist; Dietitian). Intestinal Failure nurse consultant</td>
<td>Intestinal Failure Coordinator TPN nurses (3 FTE) Lead inpatient nurse manager and nursing staff Pharmacist Psychiatrist Social Worker</td>
</tr>
<tr>
<td><strong>Team rounds</strong></td>
<td>Daily (for PN)</td>
<td>Daily</td>
<td>Twice per week</td>
<td>Twice per week</td>
</tr>
<tr>
<td><strong>Key Monitoring</strong></td>
<td>Biochemistry Weight Fluid Balance</td>
<td>Biochemistry Weight Urinary Sodium (weekly) Fluid Balance Anthropometry</td>
<td>Biochemistry Weight</td>
<td>Biochemistry Weight Urinary Sodium Fluid Balance Anthropometry Grip Strength</td>
</tr>
<tr>
<td><strong>Key medications</strong></td>
<td>Octreotide Lomotil and Imodium Codeine Phosphate Tincture of Opium PPI/H2 Blocker</td>
<td>Imodium Codeine Phosphate PPI</td>
<td>Imodium Codeine Phosphate PPI</td>
<td>Imodium (up to 60mg/day) Codeine Phosphate PPI</td>
</tr>
<tr>
<td><strong>Type of Oral Rehydration Solution Used</strong></td>
<td>Half strength Gatorade (extra salt added)</td>
<td>Diarolyte (double strength)</td>
<td>Pedialyte</td>
<td>St Marks Solution</td>
</tr>
</tbody>
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Parenteral Nutrition (PN)

As intestinal failure patients so often require hospital and/or home parenteral nutrition, these services were also reviewed. All hospitals had well established parenteral nutrition teams and all hospitals used individually compounded parenteral bags.

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<thead>
<tr>
<th></th>
<th>Cleveland Clinic, Cleveland</th>
<th>Hope Hospital, Manchester</th>
<th>Northwestern Hospital, Chicago</th>
<th>St Marks Hospital, London</th>
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<tbody>
<tr>
<td>No. of Home PN</td>
<td>&gt;100</td>
<td>~160</td>
<td>~55</td>
<td>~180</td>
</tr>
<tr>
<td>Funding</td>
<td>Health Insurance and Medicare</td>
<td>National Health Insurance – Primary Care Units</td>
<td>Health Insurance and Medicare</td>
<td>National Health Insurance – Primary Care Units</td>
</tr>
<tr>
<td>Hospital PN formula</td>
<td>Individually compounded off site</td>
<td>Individually compounded on site</td>
<td>Individually compounded on site</td>
<td>Individually compounded on site</td>
</tr>
<tr>
<td>Home PN formula</td>
<td>Individually compounded and outsourced</td>
<td>Individually compounded and outsourced</td>
<td>Individually compounded and outsourced</td>
<td>Individually compounded and outsourced</td>
</tr>
<tr>
<td>Type of line used</td>
<td>PICC</td>
<td>PICC/Hickmans</td>
<td>PICC</td>
<td>Broviak</td>
</tr>
<tr>
<td>Team Rounds</td>
<td>Daily</td>
<td>Daily</td>
<td>Twice per week</td>
<td>Twice per week</td>
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PICC – Peripherally Inserted Central Catheter

Fistulocystis

This refers to “enteral feeding via an intestinal fistula”\(^2\). While this technique has been attempted for many years it has largely been unsuccessful. The Hope Hospital, Manchester has refined this technique and are now considered world experts in the field of fistulocystis. Latest data was presented at ESPEN, and further understanding into this technique was gained while visiting the hospital. The length of distal small bowel to the feeding fistula varied from 20cm to 400cm (average 40cm) and the majority of patients had a colon in continuity. In the past 5 years this has resulted in 36 patients being able to cease PN completely.

The benefits of being able to feed someone enterally verses parenterally are huge, including:

- Reduced risk of parenteral nutrition related complications
- Bowel adaption means less complications if reconstructive surgery occurs later

- Cost benefit to patient and facility

Necessary for the successful implementation of fistuloclysis is:

- The correct equipment – as documented in their publication “Fistuloclysis Distal Feeding – information and guidance for patients and healthcare professionals”.
- Careful knowledge of the bowel present (i.e. passing the feeding tube past any loops that may result in the tube migrating back and causing displacement).
- Time for establishment of the feeding rate and training – it takes approximately 3-4 weeks of inpatient training before the patient can be successfully sent home with feeding.
- Trial of different feeds from polymeric to semi-elemental to elemental, and addition of salt to feeds.
- Acknowledgement that there will always be a small amount of feed that flows back into the stoma bag due to peristalsis movement and this is normal.

**Small Bowel Transplant**

The first small bowel transplant was performed in 1987, but there are still only few centres that offer this service. Australia does not yet have a centre that offers small bowel transplantation. Each of the units visited had a strong link with an intestinal transplant unit. This was either within their own hospital (Cleveland Clinic, Ohio and Northwestern University Hospital, Chicago), or with another hospital.

For a centre to consider small bowel transplantation not only does one require a surgeon with such specialist skills, but also to comply with international guidelines for transplantation. This means access to social, nutritional and psychological staff for full assessment pre-transplant.

Key to assessing a patient's suitability for transplant is the patient's risk of death due to parenteral nutrition complication or underlying disease, extreme reduction in quality of life or inability to accept home parenteral nutrition as a long term option.

Nutritional management of patients post transplant initially is parenteral nutrition with nil oral intake, with the slow introduction of enteral or oral foods. The aim is to fully established oral diet within 4-6 weeks post transplant.

For those patients that have a rapport with an intestinal failure unit but has had surgery elsewhere, it is important for the hospitals to have a close relationship, so that joint patient care can be maintained.

**Support Services for Patients**

National support groups exist both in the USA and UK for patients on artificial nutrition support (i.e. enteral and parenteral nutrition) and were both founded by patients. While this includes many of the intestinal failure patients, it does not encompass
those that may be able to manage at home without artificial nutrition support, although still follow a strict dietary and fluid regimen.

**United Kingdom**

PINNT – Patients on Intravenous and Nasogastric Nutrition Therapy

PO Box 3126

Christchurch, Dorset

BH23 2XS United Kingdom

www.pinnt.com

**United States**

The Oley Foundation

214 Hun Memorial MC-28

Albany Medical Centre

Albany, NY 12208-3478

www.oley.org

Local support groups existed for inflammatory bowel disease at Northwestern University Hospital, Chicago which consisted of an 8 week course. The Hope Hospital had an informal meeting for patients prior to their outpatient clinic. Patient attendance is variable but this type of arrangement is only effective given the volume of patients attending this service.

There is no support group for patients requiring artificial nutrition support nor for intestinal failure patients within Australia.

**Conclusions**

While each individual centre has a different structure all patients receive intense multidisciplinary health professional input with regular outpatient review. The Dietitian is a crucial member of this team. The results of such a synchronised service means a patient’s nutrition and electrolyte status are maximised with minimal parenteral nutrition and minimal complications. Patients are only referred on to surgery or transplant when appropriate.

The development of such a service in Australia would greatly improve patient care, and act as an excellent resource for other health professionals around the country.
Recommendations

Currently Intestinal Failure patients in Australia are greatly disadvantaged because of the lack of a national or state intestinal rehabilitation program. The medical, surgical and nutritional management of this group is perhaps one of the most complex and requires expert input. This is only possible when health professionals are exposed to this group of patients in sufficient numbers to gain that expertise, such as the development of an intestinal rehabilitation program. Steps that I will take to improve the nutritional management of this group will include:

- To complete hospital based guidelines for the nutritional management of short bowel syndrome which are currently in draft form. These will be used for the management of inpatients at Royal Prince Alfred Hospital, but will also be available to other health professionals and used as a teaching guide.

- Commence a nutrition clinic for patients with intestinal failure. This will allow patients to be referred for expert nutrition advice, although will also need to be under the care of a general practitioner or consultant. Data will be kept on the number of patients referred.

- Using current data and data obtained from the above clinic, a proposal will be drafted to set up an intestinal rehabilitation team. This will be done only after consultation with key medical and surgical stakeholders. This will be lobbied to the area health service, but also should other service enhancement grants be made available.

- Continue to make myself available for providing education in this area.

- Liaise with the Australasian Society for Parenteral and Enteral Nutrition (AuSPEN) regarding national guidelines and the possibility of developing a patient support group.