

Ospidéal
Mhuire na Leanaí,
Cromghlinn



Our Lady's
Children's Hospital,
Crumlin

Intestinal failure-Home PN

Are we failing our most challenging patient
group?

Billy Bourke

Physicians.Surgeons.....

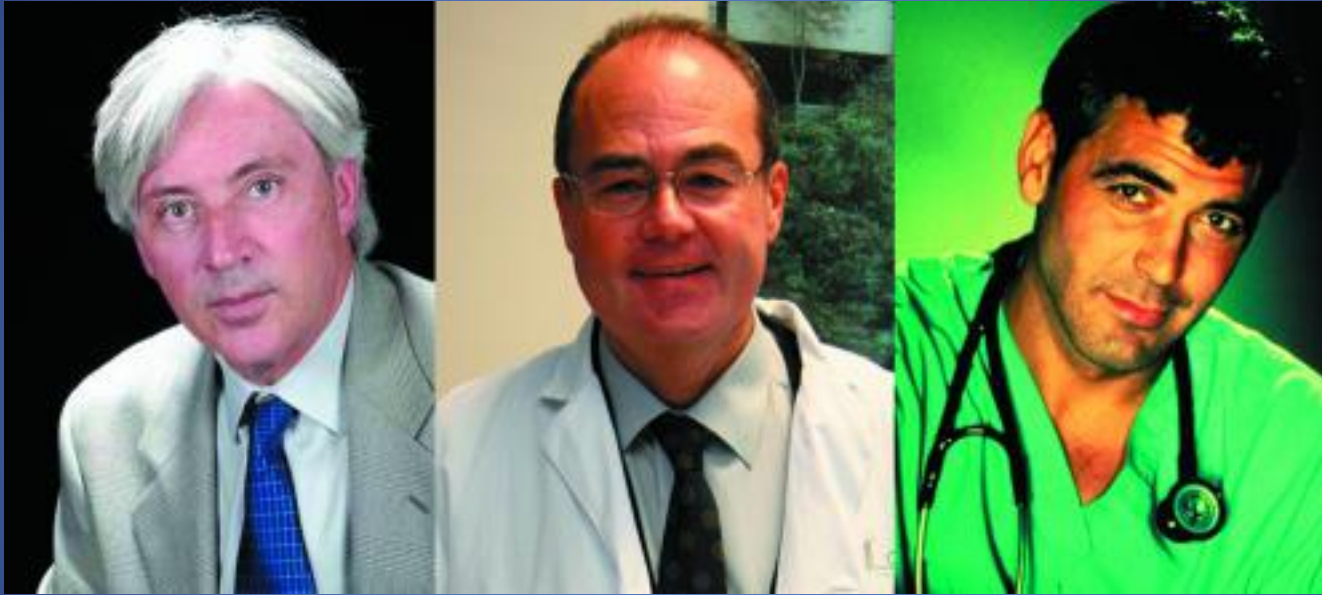


Thoughtful
Circumspect
Intellectual
Holistic



Decisive
Forthright
Proactive
....Attractive?

Surgeons are taller and more attractive than physicians



BMJ [.333\(7582\)](#); Dec 23, 2006

“The qualities that are required to be a successful surgeon appear to be mutually exclusive from those required to be a successful researcher”

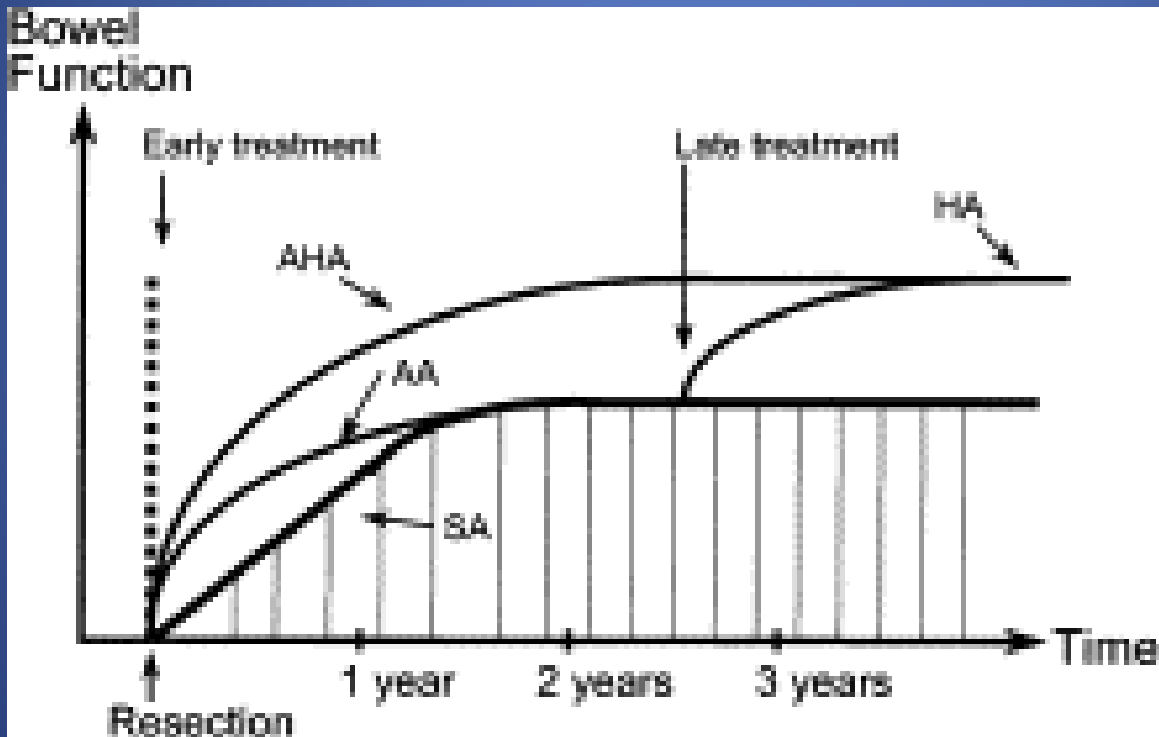
Lancet 1997

SBS- Critical Lengths NN's

- Remaining Gut Chance of Enteral Rehabilitation
 - < 40cm no ICV Minimal
 - <40cm most of Colon Longterm+
 - 40-100cm no ICV Med term +
 - 40-100cm +ICV Short term+

Adaptation

- Muscular hypertrophy/Mucosal Hyperplasia



Intestinal Failure - Incidence

- Incidence 2-6.8 /million (EU 2001)
- Prevalence (HPN) 20/million (UK 1999)
- Ireland (Children) Overall incidence = 31
11 Prevalent cases

IF/HPN - NUTRITION SUPPORT TEAM

Our Ladys Childrens Hospital Crumlin

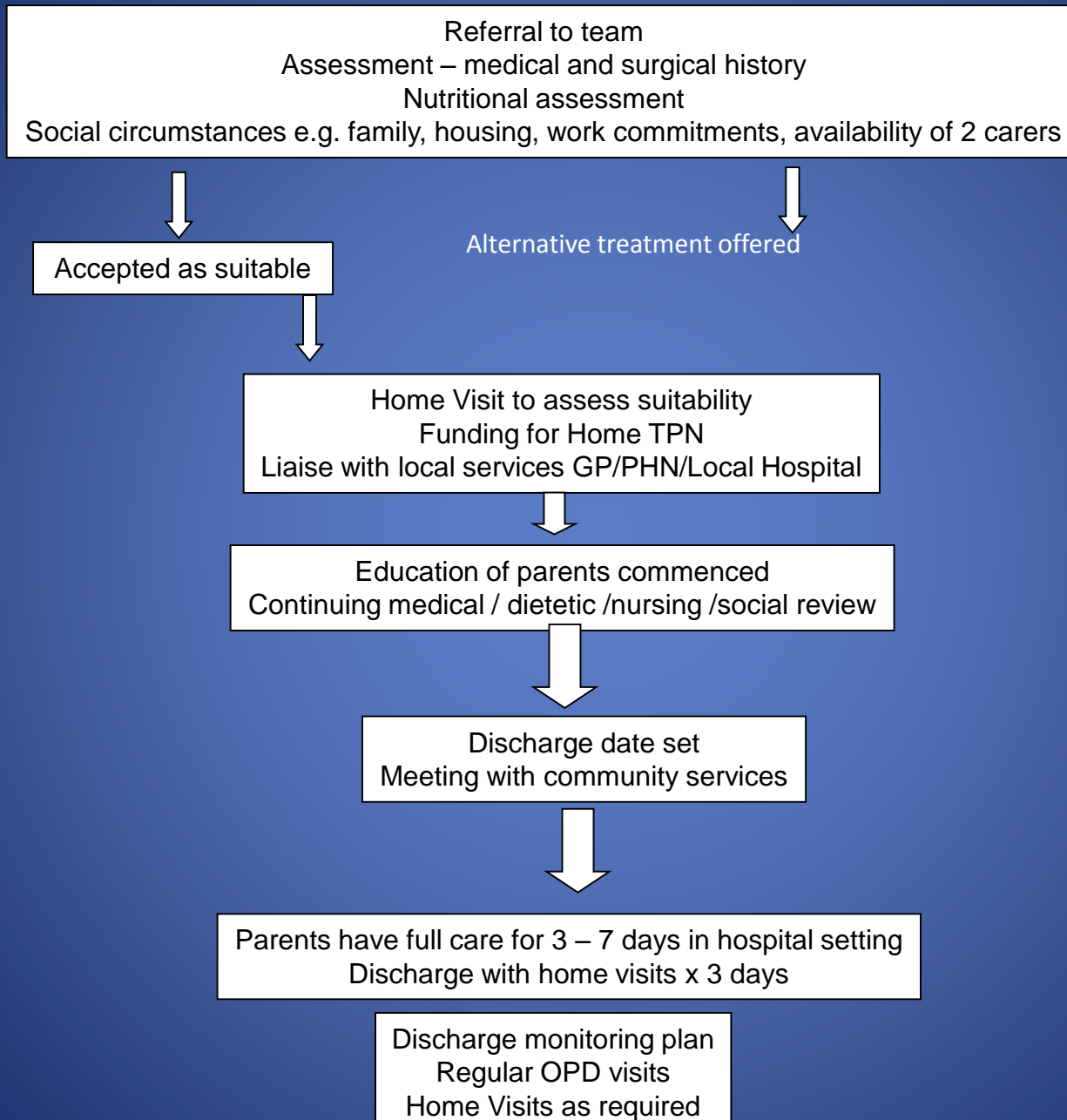
- ◎ Billy Bourke, GI Consultant
- ◎ Anthea Bryce-Smith } CNS in Nutrition
- ◎ Louise Paterson } Support
- ◎ Michelle Hurley, Senior Dietitian
- ◎ Wendy Fallon, Senior Pharmacist

- ◎ Support from Social Work; Psychology;
Administration

HPN Eligibility

- Permanent Intestinal Failure
 - Takes three months inpatient to train parents
- No life threatening co-morbidity
- Access
- Psychosocial

Home TPN Patient Pathway



HPN in Ireland - Number of patients

- ⦿ Total no of patients : 31
- ⦿ Age range: 6 Mo to 17 yrs
- ⦿ Current : 11
- ⦿ Weaned : 10 (1 transitioned)
- ⦿ RIP: 10
- ⦿ **Transitioned: 3 (2 RIP)**
- ⦿ Parental unsuitability : 1

Intestinal Failure diagnoses

| Diagnosis | Number |
|-----------------------|--------|
| SBS | 17 |
| Crohn's Disease | 2 |
| Congen Diarrhoea NYD | 3 |
| FTT/immunodeficiency | 1 |
| Mitochondrial Disease | 1 |
| Pseudobstruction | 5 |
| MVID | 2 |

HPN Patients - Current Status

| Diagnosis | Current | Weaned | RIP |
|------------------|----------------|---------------|------------|
| SBS | 3 | 8 | 5 |
| Crohn's | | | 2 |
| FTT/undiag | 1 | 2 | |
| FTT/immdef | | | 1 |
| Metabolic | 1 | | 1 |
| Motility | 5 | | |
| MVID | 1 | | 1 |

Length of time on Home PN

| Length | Current | Weaned | RIP | Total |
|----------|---------|---------------------|----------------------------|---------|
| < 1 year | 2 | 3 | 4 | 9 (29%) |
| < 2 year | 2 | 5 | 2 | 9 (29%) |
| < 3 year | 1 | 1 | 1 + 1 adult services | 4 (13%) |
| > 3 year | 6 | 1 adult services | 2 | 9 (29%) |

Quality of Life

- Family disruption
- Psychosocial stress
- Siblings
- Financial issues
- Depression

- BUT– Good QoL scores 1yr post discharge
children > parents

Cost Savings

- Dramatic reduction in hospital admissions
 - Patient at home for 8 years – only admitted for 20 days during this time = Average < 1% of time spent in hospital

Line Infections

- ◎ Reduced number of line infections
 - e.g. 12 episodes as inpatient in 17 mths ,
0 at home in 8yrs,

6yrs 3 within first 2yrs none last 4 yrs

Line Infx - Cost Savings

- Reduced number of line infections
- 10 day inpatient stay
- 10 day I.V. antibiotics
- Saving of **10,000** euro per episode

Cost Savings Overall

- ⦿ Cost of Inpatient stay = 296,000 euro/yr
- ⦿ Cost of Home service = 93,000 euro /yr

Saving of **203,000** euro per yr per child

Conclusion:

- 15 yrs after setting up HPN for Irish children there is not Adult HPN service
- Even allowing for cost of improved survival adult service likely would be cost saving
- Unprecedented in a developed economy to be without adult IF/HPN programme

Thank you