10 years experience of Home Parenteral Nutrition in Children - the development of an innovative service in Yorkshire

Gill Lazonby
Children’s Nutrition Nurse Specialist
Leeds General Infirmary
The Leeds Teaching Hospitals NHS Trust
Yorkshire, England, UK.
The General Infirmary at Leeds

Children’s Nutrition Team

- 1990  Consultant Paediatrician
- 1992  Second Dietitian
- 1992  Nutrition Nurse Specialist
- 1993  PN pharmacist
- 2003  5 dietitians, 1.5 nutrition nurses
Who gets home parenteral nutrition (HPN) ?

• a baby or child who will need PN for more than 2 months with stable medical condition
• fast track discharges for palliative care
• nutrition team discusses with the child and family and explains what it involves, in collaboration with the medical/surgical team

Diagnoses of children on HPN
Districts in Yorkshire where children were discharged on HPN

- Durham
- Cleveland

Our experience of HPN

- 26 children, mean time on HPN 11 month (range 2-33 months)
- 18 (69%) children off PN
  - 12 (46%) on oral diet
  - 6 (23%) on HEN
- 3 (12%) died
- 5 (19%) on HPN and one awaiting discharge
Our experience with small bowel transplant

- 5 patients assessed for small bowel transplant
- 3 listed for small bowel transplant
- 1 died on waiting list
- 2 transplanted
- 1 died 2 years post transplant
- 1 well 5 years post transplant

The role of the Children’s Nutrition Nurse Specialist

- acts as Key Worker
- prepare parents/carers for PN at home
- develop teaching plan and assess progress
- arrange shared care with local Children’s Community Nurse, GP & Health Visitor
- organise supply of equipment
- provide telephone support and home visits
Assessment for HPN

Medical
• metabolically stable
• cyclical PN
• good central venous access

Psycho-social
• family willing to provide high dependency care at home
• housing, financial & social circumstances
• support & respite available

Framework for the assessment of children in need and their families (DOH 2000)

Child & family

Child’s developmental needs

Parenting capacity

Family & environmental needs
Discharge planning meeting

- identify key people
- involve parents/carers
- set the agenda
- prepare the family for the meeting
- develop action plan
- chair and minute effectively
- follow up to ensure the plan is implemented

Obstacles to discharge on HPN

Housing needs
- 8 (30%) of families needed re-housing prior to discharge on HPN
- 13 children on long term PN in hospital had - 4 had unresolved housing needs and were off PN before they were met
Oliver & his family’s needs

• single mum
• no family support nearby
• lived in one bedroom flat
• no storage space

Oliver’s & his family’s needs

• re-housed in 3 bedroom house close to grandparents
• local children’s community nurse, paediatrician and GP provided shared care
• nursery place with extra support
• weekly laundry service
• respite evening once a month
Training for HPN

- anatomy and physiology related to diagnosis and CVC care
- aseptic technique
- setting up & disconnecting PN
- use of infusion pumps
- recognition & management of complications

Case history of suspected CVC infection

Presented with temp 38.5°C

Assessed in hospital, then discharge home

12 hours later readmitted, septic shock

PICU with overwhelming sepsis

Multi-organ failure resulting in death
Management of suspected CVC Infection

- guidelines updated regularly
- education for doctors and nurses
- parent held records include guidelines
- education and empowerment of parents
- **LISTEN to parents**, they know their child best

Management of suspected CVC Infection

- act on first temperature above 38.5°C
- CRP, central & peripheral blood cultures
- FBC, U&E, LFT, Ca, Mg, Phos
- assess for other causes of infection
- antibiotic policy - antibiotic locks
- treat for at least 48hours
Development of a CVC occlusion

Likely cause is a thrombus, a fat deposit or calcium phosphate deposit
• use infusion pump with pressure monitoring
• teach parents how to recognise CVC becoming stiff
• check CVC not twisted or kinked
• early intervention before line fully occluded

Development of a CVC occlusion

• occlusion guidelines
• discharge prescription for
  – Urokinase 5000 iu/2ml, CVC lock
  – Absolute Alcohol 2ml, CVC lock
• teach local children’s community nurses how to give CVC locks
Integration into mainstream school

• pseudo-obstruction
• dependent on PN since birth
• abdominal distension & diarrhoea
• short stature & tires easily
• CVC & caecostomy stoma

Successful integration into school

• planning meeting at school to identify Kyle’s needs
• develop care plan with parents for school
• referral to occupational therapist
• assessment of Kyle’s needs and the school environment
• recruitment of carer
Partnership working with parents

• age 4 years, long segment Hirschprung’s disease
• poor weight gain
• high stoma output & dehydration
• chronic enterocolitis
• re-admissions for IV rehydration and antibiotics

Management

• home parenteral nutrition
• IV replacement fluid
• gradual reintroduction of gastrostomy feeds
• treatment of bacterial overgrowth at regular intervals
### Feeding Plan for Damian SIMPSON

**Date:**

**PARENTERAL NUTRITION – All in one bag vitamin & lipid**

To give .......... ml of parenteral nutrition over ........ hr

Set rate at: ......................... ml/hr and enter

Set volume to be infused at: ...... ml and enter

When volume infused reduce rate to: ...... ml/hr and enter

And set volume to be infused at: ........ ml and enter

Pump goes into KVO (keep vein open) at 5 ml/hr until ready to flush off

**GASTROSTOMY FEED**

Neocate Advance with paediatric seravit

Set rate at: .......... ml/hr

Clear dose and volume

Set Volume at ............ ml

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### Replacement of stoma losses

Stoma losses of more than 600 mls per day to be replaced with 0.9% Sodium Chloride with 20 mmols of Potassium.

If stoma losses are more than 2000 mls per day Damian is to be readmitted to Ward 48 for review by Mr Crabbe and Dr Puntis.

<table>
<thead>
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<th>STOMA LOSSES</th>
<th>REPLACE OVERNIGHT</th>
<th>RATE OVER 12 HOURS</th>
<th>RATE OVER 11 HOURS</th>
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</table>

2000ml and over Contact Ward 48 for advice

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### Monitoring

- Parent held records
- Weekly weight & biochemistry initially
- Share care with local Children’s Community Nurse & Health Visitor
- Regular telephone contact
- Home visits
- 3 monthly HPN multi-disciplinary clinic

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Outcome

- gradual reduction in stoma output
- tolerance of gastrostomy feeds
- improvement in oral intake
- reduced nights on PN
- improved school attendance
- reduced number of hospital admissions and length of stay

The future?

- tolerance of full enteral feeding?
- complications of PN?
- small bowel transplant?
- living donor graft from identical twin?