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Mia Small illustrates the effect that parenteral and enteral nutritional support has on patients’ quality of life

**Key Words**
- Intestinal failure
- Nutrition
- Quality of life

**References**

**Further Information**
- Patients on Intravenous and Naso-gastric Nutrition Therapy
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**Living with intestinal failure**

A number of studies have examined the quality of life of patients with intestinal failure (Jeppesen et al, 1999; Richards and Irving, 1997). Common factors reported are feelings of anger, anxiety, and depression resulting from a profound sense of loss.

This loss encompasses the inability to eat and drink normally, and a reduction in independence, social and work status and control of bodily functions. Fatigue is common and significantly impacts on daily activity and social interaction. Loss of sleep associated with nocturnal infusions may affect the individual’s normal circadian rhythm, which can lead to increased fatigue and feelings of general malaise (Gulledge, 1985).

Patients receiving enteral and parenteral nutrition can experience changed appetite sensations such as hunger, food cravings, and extreme thirst. This is thought to be partly due to a reduction in the cephalic phase response that usually occurs following detection of food in the upper gastrointestinal tract (Stratton and Elia, 1999). The presence of such distressing symptoms may severely limit the ability to adhere to a treatment regimen.

The psychological impact may be such that patients could require formal support and counselling (Forbes, 1997). An invaluable source of peer support and practical advice is the patient support group Patients on Intravenous and Naso-gastric Nutrition Therapy (PINNT).

**Discharge from hospital** Preparation for discharge should focus on the individual acquiring the necessary motor skills in order to care for their parenteral and enteral nutrition. It should also cover how and when these tasks will be accommodated into their routine.

The British Association for Parenteral and Enteral Nutrition (BAPEN) has produced guidelines relating to the preparation of patients for discharge home on parenteral nutrition (Wood et al, 1995).

The quantity and type of equipment that will need to be accommodated discreetly in the patient’s home must be considered. The biggest challenge is usually where to store the dedicated refrigerator, which may need to hold 14 bags of parenteral nutrition. A subgroup of BAPEN called LITRE (Looking into the Requirements for Equipment) aims to respond to patients’ needs and concerns regarding equipment and to collaborate with manufacturers to produce new designs.

**Living with intestinal failure** The following scenario demonstrates the extent to which a parenteral treatment regimen can impact on an individual’s daily life. Sally Crespi (not her real name) is 48 years old and has had Crohn’s disease for 20 years. She has had a jejunostomy since 1997 and has been dependent on home parenteral nutrition since then. Her treatment regimen is illustrated in Box 1.

If the same facts are presented to show how Ms Crespi is affected by her condition and treatment, the impact of this regime emerges (Box 2). The 90 minutes allocated to stomal management reflects the need for meticulous attention to detail that is often required to prevent leakage and associated skin damage. Ms Crespi has had numerous operations and needs to fill skin crevices and build up uneven skin surfaces with adhesive paste, washers or flanges, before applying her stoma bag. Once the bag has been applied, patients are advised to rest for about an hour so as to promote adhesion (Forbes and Myers, 1996).

**Conclusion** The full impact on an individual’s daily life only becomes evident when the elements of the treatment regimen are mapped out into a typical day. Although this illustrates the restrictive nature of the treatment regime, it still only presents an idea of what living with intestinal failure actually means to patients.

**Box 1. Clinical Details of Treatment**

**Intake**
- Oral intake of 1 litre of fluid in 24 hours
- Parenteral nutrition volume of 3 litres daily
- Lipid infusion of 500ml twice a week
- Medication – Omeprazole: 40mg twice daily
  Loperamide: 16mg four times daily
  Codeine phosphate: 90mg four times daily

**Box 2. The Effect of Treatment on Daily Living**

**Intake**
- Oral intake restricted to five mugs of fluid in 24 hours
- Parenteral nutrition for 12 hours each day
- A 16-hour infusion twice a week, which includes lipids

**Output**
- Stoma bag emptied every 2–3 hours during the day and attached to a drainage bag at night
- Daily stoma appliance change takes about 90 minutes each day
- Ms Crespi passes urine 2–3 times during the day and every two hours overnight when attached to parenteral nutrition.