

**HOME ARTIFICIAL NUTRITION  
AWARENESS (HAN) WEEK  
starts on 3rd August 2020**

A week dedicated to raising awareness about essential life-saving nutrition treatments received by people living in the community, at home.

# Building an Intestinal Failure Service: Key Learnings

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# Introduction

We know that Rome wasn't built in a day, neither are healthcare services especially in the midst of a global pandemic. The Intestinal Rehabilitation (IR) and Complex Nutrition service at St James's Hospital (SJH) is no exception. We have outlined below the challenges faced with building the new service.

The IR service is concerned with the management of the relatively small group of patients with sustained Intestinal Failure (IF) (type II and type III). The complex needs of such patients challenge even the most experienced clinicians, necessitating management by highly trained, specialist multi-disciplinary teams (Vlug et al., 2020; Pironi, 2020). The IR and Complex Nutrition Service at SJH was established to develop a national specialist adolescent service for patients with IF at SJH and Children's Health Ireland (CHI) Crumlin. Previously there was no specialist IF unit or service for adult or adolescent patients within the Republic of Ireland (ROI). A specialist unit for paediatric patients with complex nutritional needs, including a need for Home Parenteral Nutrition (HPN) has been in place in CHI Crumlin since 2000. The case for establishing a National IR unit for the ROI is supported by findings from specialist units internationally of dramatically improved morbidity and mortality compared to treatment at non-specialist hospitals. (BAPEN, 1992; Vlug et al., 2020)

# Challenges

## Defining the service

Before the IR team came together in SJH, the Irish Society for Clinical Nutrition and Metabolism (IrSPEN) and a team of surgeons, gastroenterologists, clinical nurse specialists and dietitians at CHI Crumlin and SJH undertook the:

- task of data collection on existing services
- identification of the gaps in patient services
- creation of the vision for future services
- campaigning for these service

In adult acute care services, we have known for many years, our complex surgical and gastroenterology patients require a specialist IR team and unit. IrSPEN Special Report No. 1 published in 2013 revealed the large gaps in HPN and IR services in Ireland. The report made recommendations such as:

- national configuration of services
- quality standards and services criteria
- data auditing and outcome measurement
- clinical governance
- patient-centred care

The scope of our service centres is the management of the complex medical and nutritional needs of IF patients transitioning from IF paediatric services in CHI Crumlin to adult services at SJH. These requirements are in addition to the existing cohort of gastroenterology and surgical patients with IF also requiring specialist nutritional care. CHI Crumlin is the national tertiary referral centre for paediatric IF patients in ROI and provides a long standing, well-organised service. Before the service in SJH began, the lack of a dedicated specialist services for transitioning paediatric patients was an anomaly. The North of Ireland (NI), across the UK, Europe and developed healthcare systems worldwide, all have well developed national programmes. The complete absence of an adult Parenteral Nutrition (PN) support service in the ROI is contrary to all expert recommendations. All unequivocally support the need for national healthcare systems to establish dedicated PN support units (Staun et al., 2009) that meet specified minimum criteria for service configuration, staffing, governance and audit (Staun et al., 2009).

A challenge for the future exists where there continues to be an under resourced national service to these complex patients. The long term goal would be the establishment of a national adult IF service, based on a hub and spoke model with up to two / three regional hospitals established as support centres to

manage less complex cases. This model would streamline and improve the quality of care. A national service configured to comply with international standards would also be anticipated to reduce bed days by facilitating the move of PN inpatients onto HPN. Such an approach will achieve cost savings and improving flow between hospital and community in line with Sláinte care.

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## Building a Team

Setting up any new service requires a new team. This can be a challenging process when the professionals needed are required to have expertise in an area that cares for a patient group with a rare illness and with limited resources nationally. Fortunately, we were able to find core members of our team with such experience – consultant gastroenterologist, specialist dietitian, specialist nurse. Staggered hiring of team members meant working without a fully established team for a short period of time. In this case, the support of the existing gastroenterology team was important for continuity of care for the current cohort of IF patients. The existing team also provided essential governance until all IF team members were united.

Pironi et al. (2016) highlight the need of the multidisciplinary approach to caring for patients with Chronic Intestinal Failure (CIF). Also improved outcomes were recognised for patients in terms of reversibility, treatment-related morbidity and mortality when cared for by an expert specialist team. Once the core team was established, support from colleagues to establish a wider Multi-Disciplinary Team (MDT) was sought. It is essential that other teams recognise the need for the service and how their input can benefit this patient group i.e. stoma care, pharmacy, microbiology, nephrology, psychology, bone health and dental teams. As this is a new service establishing relationships with these teams is crucial. We are developing pathways and protocols with these teams to ensure structured evidence-based care is provided to our patients, such as:

- creating algorithms for CRBSI management
- blood and micronutrient monitoring protocol
- psychological support
- DEXA scanning and bone health follow up
- dental assessment and oral care

In addition, the surgical management of patients with acute and chronic IF requires a specialist team (Pironi, 2020) with expertise in terms of technical challenges and decision-making (Grainger et al., 2018).

## National Guidelines, Protocols and Expertise

The IrSPEN report (2013) outlined that CIF patients are currently dispersed across a large number of non-specialist hospitals in Ireland. There is also a lack of national standards and protocols around the discharge of HPN patients and how this is managed can vary between hospitals. We recognise that there is often little support for the health care professionals caring for these patients. We are aware of expertise around the country and interest for development of national expert groups to work on guidelines for care of these patients. This was a key goal to work with colleagues around the country to develop such guidelines and share their expertise.

The National Nurse Special Interest Group (NNSIG) was set up and first met in February 2020. The group is made up of nurses from around ROI - SJH, Cork University Hospital, HPN Homecare company nurses and community nursing teams. The main aim of this group was to standardise connection / disconnection of PN between hospital and community care. This is recommended by the British Intestinal Failure Alliance (BIFA) 2018. The aim of this is to reduce the anxiety of patients who are concerned about the differences in practices that can vary between hospitals and community teams.

The nutrition subcommittee of the National Clinical Programme for Gastroenterology and Hepatology (NCPGH) was established as a one of the 6 programme priorities for the NCPGH. The input of qualified nutritional expertise is required not only for Inflammatory Bowel Disease (IBD) and Hepatology but for many other GI related conditions including the complex requirements of parenteral and enteral nutrition. The aim of this subcommittee is to improve standards of nutritional care in the ROI and to allow Irish patients to benefit from best practice including the latest advances in therapy to improve quality of life, survival and minimise complications. The group consists of consultant gastroenterologists, consultant surgeons, specialist dietitians and specialist nurses.

Intestinal Failure Dietitians Network has begun as a network of dietitians around the country who collectively have decades of experience caring for IF and HPN patients, often with little support or guidance. This group was set up to provide a forum for support and shared learning among the profession.

## Logistics

Working on two busy acute hospital sites as a new team certainly presents challenges in terms of 'making space'. Outpatient clinic spaces were on an ad hoc basis at the start, fortunately outpatient clinic space became available, thankfully we now have full clinics every fortnight. The complexity of our patients care required the set-up of MDT meetings where we discuss patient management strategies, inviting the extended MDT expertise to these meetings as required. We also review new referrals and make service development plans.

When we first started the service, many of our patients required regular infusions for electrolyte replacement and IV fluids. Access to infusion services proved challenging which often meant patients were required to attend the Emergency Department (ED). Optimising medication has eliminated the requirement for regular infusions and the necessity for such patients to present at the ED.

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## Continuous Professional Development

It is vital that we as team keep up to date with the latest research and recommendations. Attending national and international conferences (pre COVID-19 outbreak) such as St. Mark's Hospital study days, National Nurses Nutrition Group (NNNG), British Society of Gastroenterology (BSG), Irish Society of Gastroenterology (ISG), IrSPEN, ESPEN. More recently various webinars are a way of keeping up to date with the practices of our colleagues in specialist nationally funded centres in the UK and Europe.

As a team we are passionate in our belief of the importance of education and training of others in the area of PN and IF management strategies. Ensuring adequate training for hospital staff is an important part of our role to ensure safe practice. Work has begun on increasing training, such as e-learning, regular ward-based support alongside updating protocols and guidelines for PN and high output stoma management.



## Patient-Centred care

As per the IrSPEN 2013 report recommendations, there is currently no patient organisation established in the ROI to support patients on home nutrition therapy. In the UK, the charity Patients on Intravenous and Nasogastric Nutrition Therapy (PINNT) is a well-established group that offer practical support, advice and empathy to patients / carers on enteral or parenteral nutrition. In conjunction with IrSPEN we were in the process of planning a patient support day with PINNT, hoping that they could expand their reach to Irish patients and carers. Unfortunately due to COVID-19 this support day could not go ahead. However, we hope to reschedule the support day as it is an integral part of patient care that is currently lacking in the ROI.

## Planning, audit and evaluation

Planning, implementing and evaluating care is a pivotal part of providing effective care. The HSE Framework for quality improvement (2016) provides a strategic approach to improving quality at all levels, from front-line to national level. It aims to foster a culture of quality that continuously seeks to provide safe, effective, person centred care. We are currently working with the quality improvement department in SJH to develop ways to audit and evaluate the services we provide.

The prevalence of CIF patients across the ROI is unknown and there is a lack of data around outcomes and complication rates of those on HPN. IrSPEN (2013) recommended to build on the important work of the Irish Nutrition and Dietetic Institute (INDI). The development of a national IF register is required in order to obtain reliable data:

- on the incidence of HPN
- to monitor trends
- to allow detailed analysis of incidence of patient type
- on outcomes
- complication rates

We have developed an IF database with interest from a number of hospitals around the country in order to accurately understand the national picture for IF patients. Again, COVID-19 has put a hold on further work on this database. When recommenced the inputting of data and resumption of ethical approval at sites around the country can begin again.

## Conclusion

The introduction of an IR and Complex Nutrition service in SJH is a positive start to improving IF services in ROI. However, there is an immediate need for further investment and development of a national framework to establish national specialist centres. This is essential to ensure access to an equitable and consistently high quality service for IF patients in the ROI. The costs of ad hoc and uncoordinated care are difficult to measure. But the IF database will provide available data to continue to lobby for IF services for the ROI. A distinction needs to be made between the model of care for paediatric HPN patients, adult patients with IF due to benign disease and patients with malignant disease. The criteria for patient selection, protocols for monitoring and specialist services will differ. Although there are many challenges involved in setting up a new service, the patient improvements witnessed are the reward.

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