



## **PINNT Short Bowel Syndrome Survey**



# **PART ONE**

## **BACKGROUND**

**PART ONE - BACKGROUND**

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## 1. About PINNT

PINNT has been providing support for people on home artificial nutrition (HAN) and their carers for 30 years. Through work with our membership and the wider community - healthcare professionals, industry and the general public - the charity is continually working to improve the lives of those on HAN.

As the medical treatments for intestinal failure (short bowel syndrome/SBS) evolve and new treatments become available, PINNT aims to help shape and support the provision and delivery of care. We want to ensure the needs of patients and their families are met, that services are equitable and that when treatment choices are available people are empowered to make informed decisions.

Whilst our members share the common factor of requiring HAN, their individual requirements are often further defined by underlying conditions. This means that they not only need to manage and maintain their nutritional status, but also additional medical conditions. Many members struggle because their conditions and treatments are hidden, and due to their HAN they appear well. By providing a platform for the views of our community to be heard, we raise awareness to highlight the medical and personal challenges faced by our membership.

PINNT has historic links with medical professional groups, and since our inception we have been recognised as a respected source to provide the patient and carer perspective in a wide range of forums. Our collaboration with doctors, nurses, dietitians, pharmacists and others allows us to contribute towards, and produce resources and materials to support and improve, the lives of our members.

The findings of a PINNT survey conducted in 2001 contributed to the 2008 document 'A Strategic Framework for Intestinal Failure and Home Parenteral Nutrition Services for Adults in England'. This was the start of listening to the patients and carers to help shape future care and services. It was evident that there was a need for equitable access to services and expertise in the management of intestinal failure.

We hope that this survey will prove to be as impactful as our last and that it will provide an insight into how our members manage their lives whilst receiving HAN.

## 2. Foreword by Dr Gabe

In the last 20 years great progress has been made in both understanding intestinal failure and the treatments that are now available for this condition.

This report by PINNT represents an important step forward as it gives patients a clear voice. The last survey of this kind conducted by PINNT was instrumental in developing better services around the country. Commissioners have been working with clinicians over the years to develop a network of hospitals across the country with the specific aim of delivering improved services to patients. This network of hospitals will be called HIFNET (Home parenteral nutrition and Intestinal Failure NETWORK) and aims to provide expert care which is more accessible for patients. The plan will be that this network of hospitals will work to the same standards and protocols and will also be centres for education and training. Change in the NHS takes time and the commissioning process has been fraught with problems as this service is unique in many ways, however, this is still going ahead.

In addition to the new intestinal failure network we are experiencing another change - the emergence of growth factors which have been shown to increase intestinal absorption<sup>1</sup>. It is hoped that these treatments, over time, may lead to a reduced need for artificial nutrition. Over the next 10 years more of these will emerge and this will be a developing field. There have also been surgical advances for patients with intestinal failure, with considerable progress in the field of intestinal transplantation over the past decade and more recently with a small bowel lengthening program for some patients with a short bowel.

Whilst we evaluate the clinical benefit of emerging medicines and surgical treatments, it is equally critical to me and my colleagues that we understand the real life impact of the services we already deliver and how any new treatment fits in with these services, to best meet the needs of our patients. Surveys such as these will help to provide the insight from a patient perspective that will be invaluable.

There are so many reasons why this survey of patients on intravenous nutrition and tube feeding is important. This survey will not just be helpful for the healthcare professionals to find out some of the most important issues that patients face but will also inform commissioners within the NHS who will take this information very seriously. One thing I have learnt over the years is that when commissioners are aware of something, they have the real capacity to make change happen in the NHS and can then help to make things better in terms of services for our patients.

I want to thank all the patients who took part in this survey. I am sure that your participation will help once again to make a difference to the healthcare service that we are so proud of in the NHS.



**Dr Simon Gabe**  
**BAPEN President**  
**Consultant gastroenterologist & Hon senior lecturer**  
**Co-Chair of the Lennard Jones Intestinal Failure Unit**

<sup>1</sup>Schwartz et al. Long-Term Teduglutide for the Treatment of Patients With Intestinal Failure Associated With Short Bowel Syndrome. Clin Transl Gastroenterol. 2016;7:e142

### **3. Introduction to short bowel syndrome**

Short bowel syndrome is a rare, sometimes life-threatening, chronic condition that occurs when part of the small and large intestine loses function. Most commonly short bowel syndrome is associated with surgical removal of over half of the small intestine (resection). This type of surgery is performed to treat intestinal diseases such as Crohn's disease, injury or trauma to the small bowel, or congenital birth defects. When the surface area of the bowel is reduced there may not be enough of the small intestine left to absorb enough nutrients from food. Nutrients such as fats, carbohydrates, vitamins, water and electrolytes are not properly absorbed into the body (malabsorption) as a result of the surgical resection.

The main treatment for short bowel syndrome is the intravenous delivery of nutrients and electrolytes 'parenteral nutrition'. Most people will self-administer their parenteral nutrition at home (HPN), once an intravenous catheter has been put in place by a healthcare professional. Alternatively, some people will have their nutrients delivered through a tube into the stomach or small bowel 'enteral nutrition'. In some cases, the need for nutritional support decreases if surgery can be done to join parts of the bowel that have previously been disconnected. Also, in some situations the intestine can regain its absorptive properties (adaptation). Unfortunately, many patients with short bowel syndrome will require life-long parenteral nutrition (PN). It is estimated that up to 1000 people in England have short bowel syndrome requiring long-term treatment with parenteral nutrition support<sup>2</sup>.

Today the UK has an international reputation for the research, management and treatment of short bowel syndrome. The teaching hospitals in the UK are extensively involved in clinical trials in order to evaluate new products and new treatments for short bowel syndrome. The results of some of these trials into medicines that increase intestinal absorption have been encouraging. There is a growing body of evidence suggesting that treatment with growth factors may complement the current standard of care for some patients.

The National Health Service (NHS) services for short bowel syndrome are delivered under the Intestinal Failure Service, with specific clinical guidance for the management of patients with short bowel syndrome.

#### **Definition of terms vary between patients and carers:**

**PN** – Parenteral Nutrition

**HPN** – Home Parenteral Nutrition

**TPN** – Total Parenteral Nutrition

**SBS** – Short Bowel Syndrome

**Line** – Central Venous Catheter

<sup>2</sup> BANS Report 2016, Artificial Nutrition in the UK 2005-2016, Adult Home Parenteral Nutrition & Home Intravenous Fluids

#### 4. Objectives of the Report

- To provide a platform for patients and their families to communicate their experiences of living with short bowel syndrome (SBS) and the treatments for their condition.
- To communicate the need for the NHS to provide patient access to new therapies for SBS.
  - NICE (National Institute for Health and Care Excellence) will be evaluating a potential growth factor which has been developed to treat patients with SBS. The treatment, Teduglutide (Revestive), is what is known as an analogue of glucagon-like-peptide 2 (GLP-2), a naturally-occurring hormone which promotes the growth of nutrient-absorbing cells on the surface of the intestine.
- To give an insight into the patient experience of the current service delivered by the NHS.
- To support the introduction of future treatments in development.

#### 5. Methodology

This report is based on the results of surveys of patients and their carers conducted between March and May 2016. The surveys were conducted by post and online and the results have been anonymised. 82% of respondents to the patients' survey live in England, 8% Wales, 7% Scotland, 1% Northern Ireland, 1% Ireland.

These surveys were sent to the PINNT membership and more widely publicised by treatment Intestinal Failure centres and associated charities.

We collected just over 400 general responses to our survey. 150 people with SBS, and 27 family members and / or carers covering issues including the experience of treatments and the impact of SBS on patients and their families' lives. The survey also collected information on wider issues but for the purpose of this report the focus is on SBS.



# **PART TWO**

## **SURVEY RESULTS**



## 1. The condition

### Causes of SBS

As there are a number of defined conditions that can cause SBS, we asked respondents to identify / confirm the diagnosis of their 'main condition' using a range of commonly used terms. Respondents reported that SBS is most often associated with surgical complications/resection/fistula, Crohn's or other inflammatory bowel disease (IBD), and malabsorption. Some other examples that respondents reported were:

*'Operation for cancer and bladder removed as well as parts of bowel and colon.'*

*'Clot in aorta which broke off and went to colon and starved colon of oxygen.'*

*'Multiple gynaecological surgery caused adhesions eventually leading to bowel surgery.'*

Short bowel (infarction/stroke of the bowel)	10%
Short bowel (surgical complications/resection/fistula)	64.67%
Short bowel (Crohn's or other IBD)	46.0%
Malabsorption	23.33%
Obstruction	8.00%
Motility disorder	8.00%
Other gastrointestinal	6.00%
Cancer (gut/bowel)	4.00%
Cancer (other)	3.33%
Neurological (brain injury, degenerative, etc.)	4.00%
Cardiac	2.67%
Head and Neck (inc. swallowing disorder)	0.00%
Metabolic disorders (inc. inborn errors of metabolism)	0.00%
Mental Health	1.33%
Renal	2.67%
Respiratory	2.67%
Surgery	8.00%
Vascular	0.67%
Other (please specify)	22.00%
<b>Number of respondents - 150</b>	

A breakdown of the conditions causing SBS as reported by respondents is as follows:

The median age for onset of SBS was reported to be 38 (range 0 – 78 years of age). It was noted that 65% of SBS patients are female.

When asked about the emotional impact of learning that their condition would lead to them requiring artificial nutrition, a high proportion of respondents cited feelings of shock (51%), fear (42%), depression (39%) or being overwhelmed (36%).

## **Diet implications**

Whilst the majority of respondents confirmed that they are able to eat solid and pureed foods, doing so had significant implications.

Some comments we received in relation to eating solid foods are below:

*'Diet varies depending on how I feel, abdominal pain and nausea. Eat low fibre diet.'*

*'Most foods with careful chewing to avoid blockage.'*

*'I can eat a little solid food, but not every day and in small amounts.'*

*'I can eat almost anything I want, and then have to pay the price later when I have to run to the toilet.'*

Fluid intake was reported to be anywhere from as and when desired to being limited to a set amount. Consumption of 1 litre of fluid within a 24-hour period was the most commonly cited set intake.

## 2. Experience of diagnosis of SBS

Almost 90% of patients received information on their condition verbally at the time of diagnosis, whilst only 25% received written information. The majority gained further information from social media and the internet (69%) and patient groups (47%). Some respondents sought information in other ways, such as meeting other patients with the same condition, reading books or medical papers, or talking to friends.

Over half of respondents said that the verbal information they received on their condition was either 'very good' or 'good', almost a third said it was 'okay', and less than 15% said it was either 'poor' or 'very poor'. Those who received written information gave similar ratings for the quality of information. 56% of respondents felt that they did have enough information made available to them about their condition, whereas 44% felt that they did not.

Almost 70% found themselves turning to other sources of information other than medical professionals, for example patient support groups and online resources, to learn more about their condition.

## 3. Current treatment for SBS

### Information and support on artificial nutrition given to patients

Information on treatment provided by healthcare professionals was given verbally in 97% of cases, with written information provided 42% of the time. 73% of patients felt they were given enough information on their treatment.

A high proportion (71%) of people sought support from a patient group as well as 49% getting support from social media / internet. Others turned to specialist nurses, local doctors, family and friends for support. The overall experience of the information provided to respondents about their treatment was largely positive.

Respondents gave us a number of comments on what they found most effective for providing them with information and support on their treatment:

*'Verbal information from health professionals was sufficient but after reading more about HPN online I found out more information than I had been told about, especially more information about long term effects/risks. But in defence of my team, I was initially only supposed to be on short term, so wasn't told about long-term issues. Psychological support was offered in the form of therapy but I refused. Told about a patient support group in the unit but was put off by the members being quite a bit older than myself, and the issue of getting to the hospital when I was not an inpatient etc.'*

*'Having the nutrition nurses, nutrition dietitian and consultant visit regularly whilst in hospital, and regular clinics after leaving.'*

*'Once the line had been put in and after a few days I was moved to Intestinal Failure unit and support was second to none. Staff were dedicated and I was told my training to take care of line myself would take 12 weeks. However, I was home in 7 weeks with full training.'*

72% of respondents felt they had enough support available to them. Comments on what additional support respondents would have liked to have been made available include:

*'Would have liked to have met other patients but hospital never seemed to have any contacts.'*

*'More information on groups like PINNT in hospital day rooms. Having someone call into hospitals and talking to patients who are having Total Parenteral Nutrition (TPN) for the first time.'*

*'With all the ongoing conditions I had, a liaison person between departments would have helped. I had to ask for help re: my diabetes, stoma supplies, counselling etc.'*

Training received for the administration of artificial feed resulted in the majority of respondents feeling confident and / or competent. Training time varied from an hour to six months, dependent on where it was delivered and who it was delivered by. Some patients received training as an inpatient, whilst others received training at home. Most of the training was delivered by specialist nurses (NHS and homecare providers). The communication around what to do in an emergency was very clear for the vast majority of patients. Comments received on training include:

*'Initially at hospital by nutrition nurse then when I went home, came to my home every day for a week till I was confident doing and understanding administering my parenteral nutrition (PN).'*

*'Specialist nurses on specialist ward 6 months.'*

*'Homecare company at home 2 weeks for my husband and 3 for myself.'*

## 4. Impact of treatment

### Key findings

On average, patients reported the following in terms of the effect of treatment on their quality of life (on a scale of 1 (unaffected) to 10 (very affected)):

- Ability to work – moderately to very affected (7.6)
- Personal relationships – moderately affected (5.7)
- Mental health – moderately affected (5.1)
- Relationships with family and friends – moderately affected (4.6)
- Ability to take part in recreational activities - moderately to very affected (7.3)

Other findings from the survey about how people manage their condition include:

- Over 90% of respondents are receiving parenteral nutrition, and over three quarters have been receiving artificial nutrition since diagnosis.
- The average time that people reported receiving artificial nutrition was 26 years. Respondents confirmed that artificial nutrition is almost always delivered at home.
- When asked ‘how many days per week do you have your feed?’ the average reported number of days was six.
- On average, respondents needed over 12 hours to administer each feed.

### Line infection

A high proportion of people (68%) receiving parenteral nutrition had experienced a line infection. On a scale of 1 (unconcerned) to 10 (very concerned), 81% had a concern of 7 or above. Other key findings relating to line infection include:

- At the time of infection, patients generally called the hospital or presented in A&E or at their hospital unit.

## Changes to treatment

Just under half of respondents reported that there had been changes to their treatment in the last six months. This included a reduced volume of feed, changes to the prescription and differences in the length / number of nights off. The most common change was to the prescription (74%), whilst the second largest was a reduced volume of feed (26%). A change in prescription was generally cited by respondents as making little or no impact.

Of those who were required to reduce their volume of feed, many reported that this had a positive impact:

*'More flexibility and freedom. Went from 5 nights to 4. Easier to travel as less baggage.'*

*'More nights off I have from PN the better. I constantly have the goal of reducing PN. Gives me an aim.'*

*'Reduction from 5 to 4 days a welcome change.'*

Alternatively, respondents who required an increase in their volume of feed reported that although it took longer to administer and therefore impacted their day-to-day lives, the change made them feel significantly better in terms of their health.

Overall, respondents felt their condition and changes to their treatment were well managed by their doctors and medical professionals. Patients also had good access to their treatment unit to discuss any concerns and were well educated on the procedure in an emergency.

48% of respondents reported having to take additional medications (i.e. other than artificial nutrition) on a regular basis. Some extracts from the responses are below:

*'Injections e.g. Vitamin B12, vitamin D, iron infusions and tablets: calcium, folic acid, Domperidone, Zantac, Creon, Citalopram.'*

*'Intravenous (IV) antibiotic and regular iron infusion medicines.'*

*'Other medications: Omeprazole, Forceval®, Warfarin, Prednisolone, vitamin B and vitamin D injections.'*

*'I need 1 litre of Hartman's fluid every day to maintain hydration. I have an injection of Tinzaparin every day to thin my blood. I drink 4 sachets of Dioralyte every day to maintain electrolytes.'*

## Practical implications

The vast majority of patients (99%) have to store a lot of equipment at home in order to administer their treatment, and many (55%) have to purchase extra storage for their feeds and medical supplies. Dedicated refrigeration is supplied to all parenteral nutrition patients. Supplies are delivered on a fortnightly basis in the majority of cases (68%), with a further 24% receiving weekly deliveries. Delivery of re-supplies resulted in the following comments which indicate the impact of this service:

*'The homecare company text with a 2-hour slot for next day.'*

*'Normal wait 4 hours. Otherwise I end up waiting all day. Twice having to open the door midway through a feed.'*

*'6 hours every Thursday fortnightly.'*

*'Driver has a key. However, I stay in as I'm not sure who will turn up.'*

*'Delivery man has a key so no waiting time.'*

In terms of administering the actual feed, this is carried out solely by the respondent in over 75% of cases, with family members also supporting the administration as and when required. On average it takes respondents 23 minutes to put each feed up and 17 minutes to disconnect. Respondents shared their experiences of when and why they require help with administration:

*'Only need help when unwell with symptoms or fatigue. Easy to make mistakes.'*

*'If I have been very poorly then I require help lifting, inserting admin sets, injecting vitamins into bag.'*

*'IV fluids 3 night a week for 12 hours. Difficulty in managing stoma - high output. Nurses take care of my connecting and disconnecting. At the moment I find it impossible to do both.'*

*'Husband holds up PN bag so I can prime giving set. Too heavy for me to hold up in air and wait for the fluid to run through.'*

*'On bad days when I'm in excess pain or dehydrated, my wife helps as my concentration isn't sufficient. It can be difficult lifting 3500ml bag.'*

*'Rheumatoid Arthritis cannot grip the dressing, cap over port, insert giving set into feed bag and metal forceps are used to remove caps from sodium and heparin injections.'*

*'My wife does everything in connection with administration of the feed. I cannot do it myself, a fundamental problem is the weight of the bags (approximately 4kg) which I cannot lift. When the bag is first administered I have to carry it on a wheeled trolley.'*

Since starting artificial nutrition, 37% of respondents had not regularly been on holiday or taken a short break away from home. Some responses received are as follows:

*'Have not found any helpful travel agents who can guarantee my needs will be met. Airlines very unhelpful. Logistical nightmare. Insurance companies either cover me and not my equipment or vice versa. Or they charge very high amounts with a small clause in the contract which is not worth the risk.'*

*'Going on holiday would be too daunting. Too much to manage such as cleaning stoma etc. It's too much to do.'*

*'I don't know how to go away or how to go about it. I desperately need a holiday but it seems even that is controlled by TPN. It all seems so much bother to go away.'*

*'Only once, not regularly.'*

*'Too much organisation and worry, also I need a fridge large enough to take 3.5 litres PN feeds.'*

Over a 12-month period, respondents said they took both short (more than 2 nights) and longer (more than 7 days) breaks. The most visited destination was the UK followed by Europe, although 30% of respondents travelled internationally.

Respondents generally transport all medications with them on any travel activities, with a much lower proportion having homecare companies deliver to the destination or the departure point. 70% of patients have letters explaining the need for the medications to allow travel. Patients are provided with packaging for cold-chain process (2-8°C) in around 70% of cases. Some comments received from patients are below:

*'It is a nightmare. Travelled a few times in 19 years with my TPN but only for 1 night stays. Had to pack fluid and ancillaries into car along with children and dogs. It is tricky and a nightmare to remember everything and free up space for everything.'*

*'Difficult to pack supplies. Lifting and finding room in a small car is tricky.'*

*'Holiday in England for ease of transportation.'*

*'Don't mind travelling with extra luggage but it can be difficult to arrange having access to a fridge to keep the PN cool so I hope to be able to use off the shelf bags for holidays in the future.'*

*'For my big holiday to Canada, the homecare company had everything boxed up ready for me and met me at the airport with everything ready to go (which was super helpful and less stressful!) For my short breaks, 1 or 2 night away around England, I just pack everything up myself and use a portable fridge/cool box to transport my feeds. When I attended a music festival, the homecare company provided me with off the shelf bags so I wouldn't need to worry about keeping my feeds cool.'*

*'Takes a lot of planning, also hard and tiring.'*

*'For a week I have 2 cases which together weigh approximately 50kg.'*

*'Do not fly, go on cruises so much easier and staff are really supportive.'*

*'When travelling abroad it is more convenient to take off the shelf bags of TPN as they don't need a fridge. I also use a strong suitcase to carry my ancillaries abroad.'*



## 5. Viewpoints from families and carers

When asked to comment on the overall health of, and changes they had seen in, the person they care for since diagnosis and commencement of treatment, families and carers told us:

*'During the initial stages of [her] illness from 1st September 2007, her health fluctuates between good and bad days. Her condition has seriously affected her and I would describe her overall health as average.'*

*'Short bowel syndrome has had an effect on his fitness since having the syndrome, but this is improving all the time through his own determination. But his health is generally good.'*

*'I believe as my wife has grown older, her health and quality of life has deteriorated much quicker because of this condition and the medication she takes to get through everyday life. Because of long term use of steroids she has developed osteoporosis, rheumatoid arthritis and a chronic skin condition. She has become physically very weak and gets tired very quickly.'*

*'[he] gets very tired easily. Small things have become major things like getting washed and dressed in the mornings tends to take it out of him. Needs help getting socks and shoes on.'*

*'Has very bad leaks [stoma bag] every day, up to 8 a day. Sometimes, can't go out anywhere any more. Changed personality, gets very depressed. He misses food so much, being on TPN. 7 days a week x 14 hours. Just sad because no one can come up with bags that stick. Also he is limited to 1 litre of fluid per day, gets so thirsty.'*

*'My husband's life has certainly improved since commencing artificial nutrition. He remains unable to work and is unable to participate in sporting activities but these are due to other medical ailments. All our family and close friends are aware of the artificial nutrition being received by my husband and offer support.'*

*'Activities have changed tremendously. [he] loved to go walking with a rucksack on his back. Enjoyed going on day trips or longer trips especially abroad. He is restricted from doing things in the house like decorating, gardening and DIY.'*

*'[he] has definitely been limited in his career due to his condition. His condition restricts his travel day-to-day, so he has not been able to take a number of promotions as he can't do the commuting. He also gets very tired so working extended hours is not an option. Recreationally, his condition limits certain activities at the weekend and late nights are not an option due to needing to get on his TPN. He also rarely drinks as it makes him ill so missed out on social opportunities as feels restricted.'*

Families and carers also provided insight into the personal impact on them of caring for someone with SBS:

*'Initially I found myself being continually tired. This was due to the fact I had to care for [her] and also carry out the procedure to connect her up to the TPN every day for approximately eighteen months. When she was well enough to do it herself, we still had days when she was very ill and whilst not as frequent, she still has bad days. For me personally, I have a continual worry in the back of my mind wondering whether if she is ok in my absence. I have had many down days however this has not in any way affected me as much as it has [her].'*

*'My life has become secondary to looking after my wife.'*

*'I can no longer work. We no longer sleep due to nappy changes etc. And in many ways our lives are no longer our own. My mental health has been affected for the better/worse - a change of priorities.'*

*'I also finished work early as his condition was very poor but as time has passed we have learnt to work around things and still try to enjoy ourselves as much as possible.'*

*'Caring for [him] has taken over my whole life 24/7.'*

When asked how long they spend each day caring for the person with SBS, most respondents said they spend 24 hours a day doing so. Whilst 60% of carers and family members felt that they had enough information about the condition of the person they assist and the NHS treatments and services available, 40% said they do not.

*'I get no support whatsoever. When I take her to the hospital on routine visits or the local GP no one asks how I cope with looking after her. However, I do not want them to as it is my wife who has to live with this awful condition not me. So as long as I am able to I will do whatever is necessary to help and look after her day to day.'*

*'Yes and no - I've been both lucky and unlucky, lots of positive and negative help. The support network side of things is more helpful than professional help! I would like to be more involved in a network of support rather than simply receiving daytime/night respite (which we are not going to get once we have moved to Suffolk temporarily).'*

*'After [her] operation 2 years ago we knew it would be life changing. Living with a patient with a high output stoma and relying on IV fluids is difficult at times but in a way has made us stronger. A routine is imperative.'*

*'On the whole we both get really good help etc. And we do appreciate it, but sometimes we feel communication is not very good. We always had nice holidays before, but find it very hard now to get management of TPN to give us permission to have just a small break, somewhere near here, because they always say they haven't got nurses to send daily, but they have patients already in these places.'*



# **PART THREE**

## **CONCLUSIONS**

## Conclusions

SBS is a condition that is usually caused by surgical treatment of a number of different diseases. Many patients will have undergone long-term treatment for an underlying condition before surgery has led to the development of SBS. Over the long-term, many patients have been managing, and will continue to manage, a number of symptoms relating to different conditions whilst receiving HAN. This, therefore, is a diverse patient group with broad and considerable treatment needs.

Diagnosis of SBS has a major impact on both patients and families - in the short and long-term, this condition is life altering. At the point of diagnosis mainly verbal information is delivered, and based on the results of this survey there is an indication of an unmet need for a greater level of reliable 'take away' written information for patients and families to understand the nature of their condition.

The psychological impact of being diagnosed with SBS was notable, leading to feelings of shock, fear, depression and being overwhelmed.

Our survey found that patients are committed to a demanding regime when receiving HAN. On average, respondents reported spending 6 days a week receiving their artificial feed at home, with each daily feed taking at least 12 out of 24 hours to administer.

Whilst the majority of respondents reported being physically able to consume varied quantities of solid or pureed food, this was accompanied with complications due to the digestive issues that go hand in hand with this condition. For example, whilst an individual may partake in a family meal they will need to plan around the consequence of doing so – have ready and easy access to toilet facilities.

Respondents homes have been well set up to accommodate HAN, with dedicated fridges being supplied to all parenteral nutrition patients. Training levels are to a good standard, leaving patients feeling confident to carry out treatment themselves. Patients reported feeling well looked after by the Intestinal Failure Service and NHS multi-disciplinary teams, whom are working well with outsourced homecare providers. Any changes to treatment are well managed by both the care team and patient resulting in a positive outcome in the majority of cases.

When a line infection occurs, patients know the protocol for treatment. It is noted that these infections are a recognised complication for patients receiving parenteral nutrition.

This treatment regime (HAN) leads to a restriction of movement and dictates the need for a high level of forward planning for patients and families, due to the fact that daily life is largely dictated around their treatment. Many respondents spoke of days off treatment as a welcome break and felt they were afforded a greater degree of freedom as a result.

The ability to travel is largely dictated by the general health of the patient and family / carers. Considering the weight of each feed bag (reported as weighing 4kg), the storage requirements, equipment needed to physically administer the feed and the physical capability of the patient, patients have to be in the right position to maintain their nutrition status whilst away from home. Transporting the treatment away from home can prove highly challenging and many deem travelling a great distance too difficult. This places restrictions on their lives, both in work and recreational aspects.



Families and carers largely felt that whilst artificial nutrition has provided improvement to the nutritional well-being of the person they care for, they noted a marked impact on how their own day-to-day life has been impacted since the commencement of HAN. Respondents spoke of adjustments to their own lifestyles in order to provide care, for example giving up or reducing work hours and forgoing recreational activities. In a number of cases families and carers identified a greater need for support to help them cope with this lifestyle adjustment.

Whilst patients, carers and their families are receiving good levels of care and support, there are areas of unmet need that should now be addressed to improve the overall quality of life. Over the coming months PINNT will be looking at how these needs should be met, to further improve the quality of life for people receiving HAN, their families and carers.

**PINNT would like to thank everyone who took time out of their busy lives to contribute to this survey.**

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