



Price £5.00  
Free to Members

# Online

April 2007

In association with



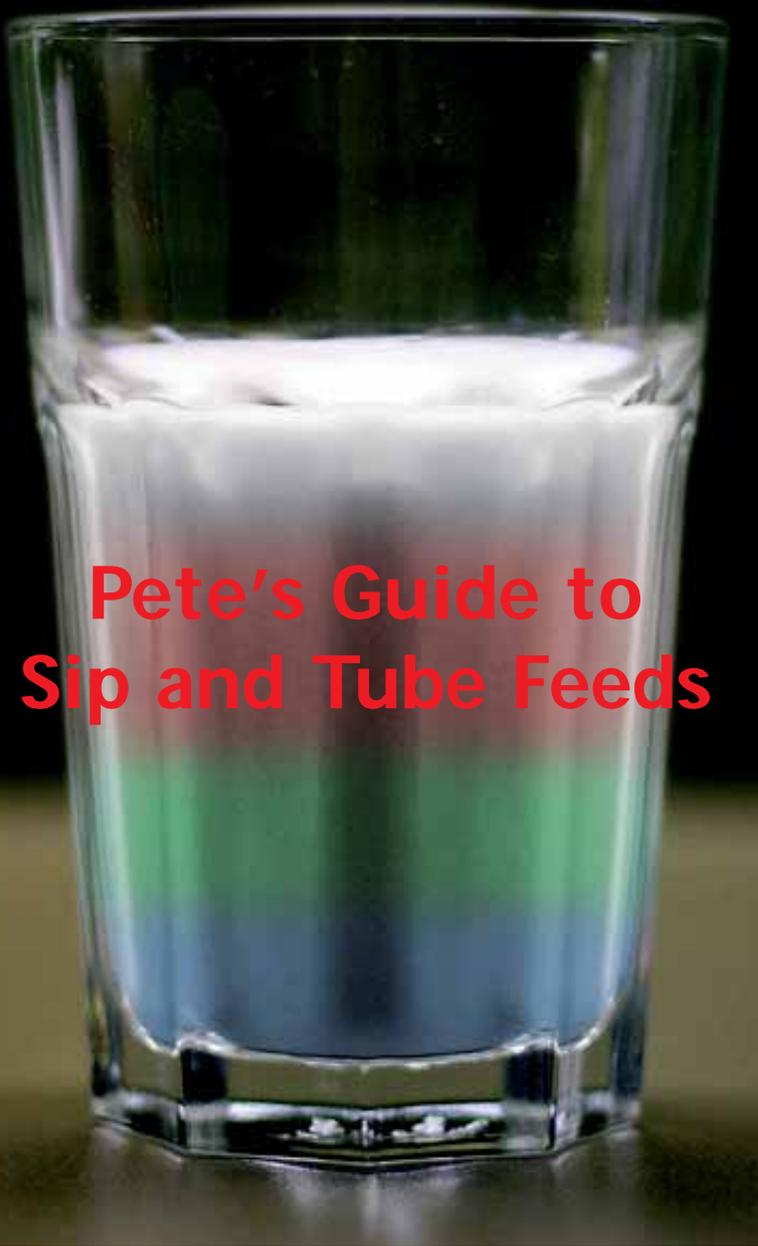
**Dietitians and other health professionals now have a vast variety of products available to increase people's nutritional intakes.** These come as drinks, powders and mixes, some taste nice, some are horrid, some must be given through a tube, lots of them have silly names and many are rumoured to cause diarrhoea.

The most frequently used products to try to build people up are called sip feeds. These often come in small cartons but some have to be made up with milk or water. Some of the carton style ones are classified as "nutritionally complete" and are suitable as a sole source of nutrition. This means you could live off them entirely and you wouldn't need to take any other food to survive. So if you were going to an inhospitable environment where you didn't want to risk eating the food, such as a trek through the jungle or a visit to a UK holiday camp, you could just live off these products alone. Examples of nutritionally complete sip feeds, which are usually milky and nicer chilled, include Ensure Plus, Fortisip or Fresubin Energy. Some even have fibre, or roughage, to keep your bowels regular e.g. Enrich Plus or Fortisip Multi Fibre. Depending on your age, weight and gender you could live off around 5 – 7 cartons a day and you wouldn't need anything else. Most people have around 3 cartons per day in addition to food to boost their intake.

If you can't stand milk there are some juice style sip feeds like Provide Xtra, Enlive Plus, Clinutren Fruit, Fortijuice or Resource Fruit Flavour Drink. Although they contain about the same amount of calories and protein as the milky versions (approx 300kcal, 10g protein per carton) and a lot of vitamins, they are not nutritionally complete. This means you can't live off them alone and you would need to eat some food to get essential fatty acids and some other nutrients. Again they are nicer chilled and most people have around three a day as a boost to their food intake.

The tastiest sip feeds are probably the ones that come in sachets and have to be mixed with fresh milk eg Scandishake, Calshake and Enshake. These taste great and I would readily drink them myself if it wasn't for the fact that the 600 odd calories and 12g of protein they contain wouldn't be good for my middle age spread! You do need to have some food in addition to these to get all the nutrients you need.

*Continued overleaf*



## Pete's Guide to Sip and Tube Feeds

### IN THIS ISSUE

- Pete's Guide to Sip & Tube Feeds Pg 1 & 2
- The Trouble with Hospitals Pg 5
- Reflections Pg 6,7
- The Coldchain Pg 8,9,10,11
- Readers' Experiences Pg 12,13
- Post Room Pg 14,15

Continued from Front Cover

There are some savoury varieties of the carton sip feeds, including one that you just add hot water to called Vitasavoury. This one should be popular with people who like Cuppa Soup or Pot Noodle – so in theory it would be ideal for students or members of the 70s rock band Slade.



Carolyn Wheatley (left) and Pete Turner (second left) giving their impersonation of a 70s rock band

All these products come in a huge variety of flavours and you can usually find one you like – but please tell your dietitian or doctor if you don't like them, as they can be quite expensive for the health service. Don't be like one lady I saw in hospital who said she couldn't stand her carton sip feeds. When I offered to cross them off her prescription sheet she said "Don't do that – my grandkids love them when they come in to visit me!"

Interestingly there is a black market for sip feeds. Some bodybuilders mistakenly believe they will give them huge muscles, which isn't the case if they are already eating a good diet. So any ladies prescribed sip feeds needn't worry that they'll end up looking like Arnold Schwarzenegger – or develop his silly accent.

Some people are unable to take nutrition by mouth and have tubes placed to be fed through, such as naso gastric tubes (from the nose to the stomach) or tubes directly

into the stomach e.g. PEGs. Some of the nutritionally complete sip feed cartons can be poured directly in to PEG type tubes (bolus feeding) whereas others come in sterile bottles or pouches and are infused through the tube using a pump.

The bottle and pouch type feeds are often categorised by the number of calories per millilitre. For example Nutrison Standard, Isosource Standard, Fresubin Original and Osmolite contain one calorie per millilitre (ml). Less intelligent or lazy health professionals may like these, as it's easy to add up the number of calories you're giving – 1500mls gives 1500kcal.

Higher energy feeds such as Ensure Plus, Nutrison Energy Plus and Fresubin Energy contain 1.5 calories per ml, making feeding over shorter periods possible by using a smaller volume. For example, a 1000mls of a high energy feed given overnight will give 1500kcal.

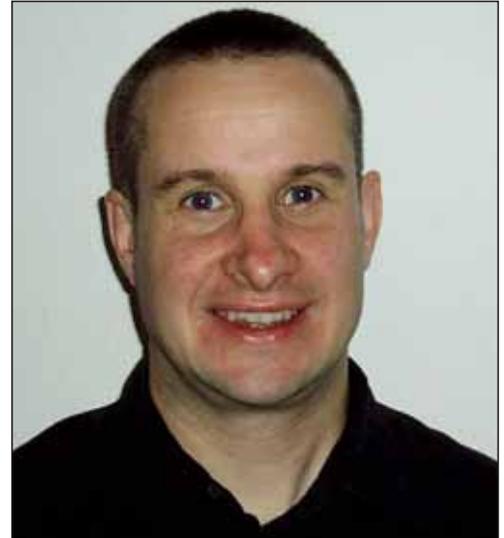
Some tube feeds are classified as specialist feeds. These include ones that are already broken down so they can be easily absorbed by people with certain gut disorders e.g. Perative, Peptamen, Pepti or Survimed OPD and Elemental O28. Other types of specialist feed are designed for people with kidney problems who require low fluid, low salt feeds e.g. Nepro.

The most commonly used tube feeds contain fibre to help maintain healthy bowel function and examples are Jevity, Nutrison Multi Fibre, Fresubin Original Fibre and Isosource Fibre. Studies show they do reduce constipation and diarrhoea.

As mentioned before, there are lots of rumours that the feeds and sip feeds cause diarrhoea. However, many scientific studies have shown that this is not the case. Although patients on sip or tube feeds may sometimes get diarrhoea, studies have shown that it is usually something else like antibiotics or syrup medications that are causing the problem. The bottom line is: don't blame the dietitian for diarrhoea –

blame the doctor or pharmacist! Remember, though, that whatever the cause of diarrhoea it can almost certainly be treated – so tell your dietitian, doctor or pharmacist.

In conclusion, there are a huge variety of products available to help you meet your nutritional needs. If you don't like the one you're on or think it doesn't suit you, speak to your dietitian, as a more suitable product can almost certainly be found.



Pete Turner, Senior Nutritional Support Dietitian Royal Liverpool University Hospital

Pete qualified as a dietitian in Leeds (1990) with a Post Graduate Diploma following a degree in pharmacology from Manchester. After gaining a Masters in Health Sciences, he worked as a Basic Grade Dietitian at Manchester Royal Infirmary before moving to the Royal Liverpool University Hospital (RLUH) in 1992. Specialising in parenteral nutrition, enteral nutrition and critical care, he has developed many protocols in these areas in association with RLUH's high profile nutrition team. He has recently taken over as chairman of the Parenteral and Enteral Nutrition Group (PENG) of the BDA as well as being an active member of the BAPEN Programmes Committee.

## MEMBERSHIP RENEWALS

It is that time of year again when membership renewals are due. You will be receiving a form during April, which is your renewal form. Please complete **ONE** form per member in your household and return it to me with your membership fee and any donations you wish to give.

If you are a tax payer, please fill in the gift aid section, as we can claim your tax back on your membership fee and any other donations.

If you give a donation by standing order/direct debit, please still return your completed form and write on the bottom that you already give regularly (finances and renewals are two separate departments). This is very important because, without your form, I cannot renew your membership.

If you do not send back your form by 1st May 2007, then you will not receive any more copies of Online and your membership will be cancelled. In addition, if you have booked the 20th Anniversary Weekend Celebration your subsidy will not be applicable and you will be charged the full rate.

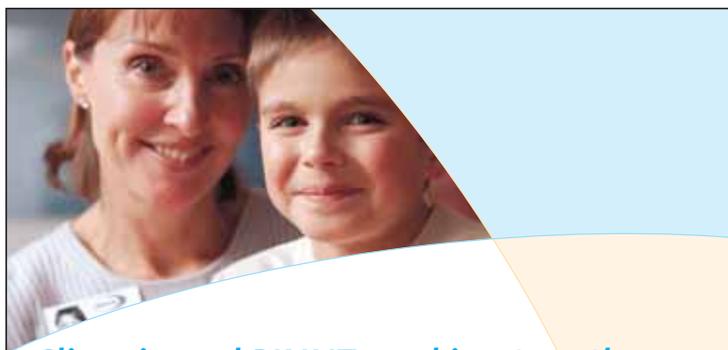
Last year PINNT spent an extra £70 sending out reminders for renewals and we feel this is an unnecessary expense. Therefore **NO** reminders will be sent.

Sarah Green  
Membership Secretary

# We're Having a Party!

Everyone was sent details about the 20th Anniversary PINNT Event back in February. If you still have not booked and are considering going, then don't delay - enquire today.

Information is available by ringing Carolyn or by visiting the members' area on the PINNT website.



## Clinovia and PINNT working together to help Darren get home sooner.

Our partnership approach to best practice ensures HPN patients receive the support that they need, while continuing to benefit from high quality clinical care in the comfort of their own home.

Find out how we can help by calling 0800 328 4423 or email [welistentoyou@clinovia.co.uk](mailto:welistentoyou@clinovia.co.uk)

Head Office: Clinovia Ltd, Scimitar Park, Roydon Road, Harlow, Essex CM19 5GU  
Telephone: 01279 456789 Fax: 01279 419900 Email: [enquiries@clinovia.co.uk](mailto:enquiries@clinovia.co.uk)



A member of the BUPA group

PINNT would like to thank Clinovia for their support with this edition of Online. In addition to this sponsorship, we work closely with Clinovia throughout the year and always welcome their support with projects and events.



## FROM THE CHAIR

Just to let you know that the official PINNT telephone number now has a new answer machine. If you left a message towards the end of last year and did not receive a call back it was due to a malfunction on the machine. Sorry, but hopefully the new machine from Santa will be much more reliable. One thing - please speak slowly and clearly - it does not matter how good the machine is, if you speed through your message I will not be able to decipher the name and number of the person who needs the call back.

We are always happy to receive donations - please contact us if you have a fund raising activity or are prepared to have a collecting box for PINNT.

*Carolyn*  
Chair PINNT

## FROM THE EDITOR

Summer's on the way so if you are thinking about holidays, remember that preparation and planning are key to a good holiday. We'd love to hear about your holiday experiences, so please send us your top tips for travelling and also your stories telling us how you managed your feeding routine whilst making the most of your summer holiday.

*Barbara*

Online Editor



## PINNT PRIZE POT

The winners of the PINNT Prize Pot for October 2006 are:



1st	Mrs Wendy Burns	£113
2nd	Mrs Kerry Hunt	£68
3rd	Linda Lockie	£45

# REGIONAL REPORT

## Scotland

We had a wonderful meeting in December with over 40 people attending - it was great this time as we had a few of our families with children attending. They are an inspiration and it is also inspiring for the families themselves to meet our members who have been on TPN for many years.

This meeting was different because for the first two hours we had the representatives from the pump companies showing us the new IV pumps that are replacing the Baxter 6060. This brought about a lot of discussion as many of us had not seen them before - now we are able to go back to our healthcare professionals with our requests.

We then had our Christmas party and raffle. It was so great to see everyone enjoying themselves and catching up with one another. I am delighted to say that we raised £65 from our raffle and we all loved every minute of it with the kids all running around. It's hard to believe that another year has passed and I want to thank everyone for all of their support during 2006 and I look forward to your continuing support throughout 2007.

Sharon Bell



## REGIONAL CO-ORDINATORS

### East Anglia

Jackie Huff 01767 225631

### West Midlands

Teresa Culverwell 0121 520 7179

### Scotland

Sharon Bell 0141 959 6701

### South East

Carmel Laverty 01372 275420

### Wales

Letty Johns 01792 521618

### Northern Ireland

Raymond Toulson 028 9260 4705

# Readership Survey Results

A big thank you to the 51 readers who completed our survey. Some people chose to leave some sections blank, so the following results will reflect this. 13 respondents were interested in enteral nutrition, 21 in parenteral nutrition and 8 were interested in both.

The features voted most useful and enjoyable in Online were readers' experiences, the post room and medical and healthcare updates. Least popular were reports on PINNT executive meetings, regional reports and updates on equipment.

The most popular of the new features suggested were interviews with readers about their experiences, interviews with healthcare professionals, 'Ask the Expert' and articles on personal relationships and family dynamics. Least popular were themed editions and features about work, holidays and artificial nutrition in other countries.

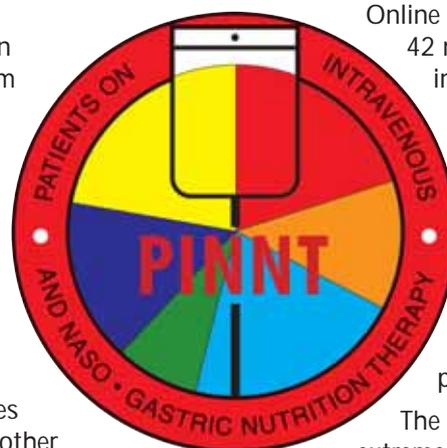
16 people would prefer three editions of 20 or 24 pages per year whilst 22 people voted for four editions of 16 pages per year.

One gentleman created his own box labelled '4 editions of 20 or 24 pages per year'. Okay, message understood and we'll try to make Online as big as possible (as long as you continue to send in your contributions!)

Online was the main point of contact with PINNT for 42 members; 22 regularly used email and the internet; 18 had visited PINNT's website; 22 wanted to see additional features on the website and 30 wanted to see dedicated pages for Half PINNT members.

Everyone who offered to contribute to a future edition of Online has been replied to personally, although a couple of people forgot to include their contact details, so if you offered to contribute but haven't heard from us, please get in touch again.

The information gathered from this survey has been extremely useful and future editions of Online will reflect your chosen favourites. And remember, it's never too late to let us know what you think - just telephone, email or drop us a line with your suggestions.

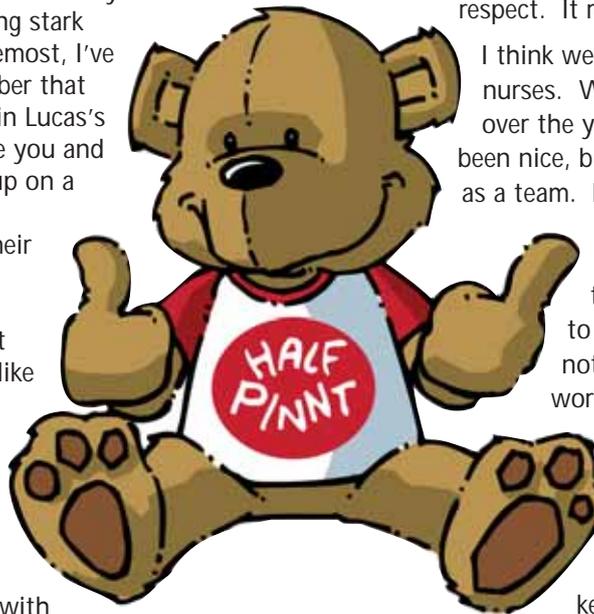


# The Trouble with Hospitals

I don't like to moan ... OK, well maybe I do sometimes ... just a little! But if I allowed myself to indulge in 'the moan' whenever the opportunity presented itself in the course of caring for my six year old son, Lucas – then 'the moan' would become a full-time occupation, and frankly – I just don't have the time for that. So, solutions had to be found, and I feel I've somehow stumbled across a balance that works (most of the time) so I thought I'd share this with my fellow members of PINNT.

So - the name of the game is to get the treatment and support that you need from the hospitals and clinics - for yourself or the person you care for - without going stark raving mad in the process! First and foremost, I've found that it's very important to remember that the doctors and nurses who play a part in Lucas's care, are in fact, just ordinary people like you and me. We have a tendency to put them up on a pedestal, assume everything they say is right, and feel bad about questioning their knowledge, or disagreeing with their decisions, for fear of being made to feel stupid. But the bottom line is, they get up in the morning and go to work just like everyone else, and while they deserve every respect for their expertise, so do we for what we do.

Probably one of the most frustrating things about seeing the medical staff is having to go over all the details of what needs to be done, and where you are at with the care regime. But, if you keep in mind that they are normal people, then it becomes easier to forgive their apparent lack of memory. I found it very useful to my sanity to remember that I am an expert on Lucas. I care for him day-in and day-out, and I know every nuance of his behaviour, and what it means in medical terms. I know what his medical needs are day-to-day because I am living it, but I cannot expect the medical team to remember all of that information too. On a daily basis, I dread to think of the amount of patients that are seen by the medical staff, and when I see Lucas's hospital file - several inches thick - I cannot reasonably expect that the doctor will have waded all the way through it before seeing us, and will therefore recall exactly where we were up to. Letting go of this expectation makes my life a lot easier. I go to clinics with Lucas, prepared in my own mind, and with questions and queries written down on paper, and I make it (rightly or wrongly) my responsibility to know where we're at, and what needs to be done.



I recall once, a couple of years ago, I had a long list of outstanding queries about Lucas's health that we never seemed to get around to sorting out in the hurried clinics. So I gritted my teeth, and wrote a lengthy – but non-accusatory - letter to the consultant, listing the problems. I really didn't know how she'd take such a direct hit of my concerns, but I was very pleasantly surprised when she called me at home, and took the time to go through each problem one by one. She even thanked me for pointing out all of the things that were outstanding, and as a result, I now feel that I can raise any concerns that I have in the clinics, and we have a relationship built on mutual respect. It really does make things a lot easier.

I think we're also very lucky with the clinical nurses. We've seen many of them come and go over the years, and as a general rule, they've all been nice, but the two we have now genuinely work as a team. By remembering that they are 'normal' people like us, I've found it works well to establish some common ground with them. Just talking in general, and getting to know a little bit about them as people, not just nurses, has paved the way for good working relationships between us. When I call with a problem, it helps that I feel genuinely listened to, and they almost always act upon the problem. But again, if they don't, I don't sit around thinking the worst of them. I try to keep in mind just how busy they are, so if the promised follow-up calls don't come, then I take it upon myself to call back and give them a gentle nudge – they really don't seem to mind!

In addition to all this, I keep a detailed medical file for Lucas, which I take with me to all his appointments. I keep a record of changes to his medicines and HPN regime, height and weight, infections and procedures etc., so that when I'm asked a question, I can usually find the answer quickly. It took a fair bit of rooting about in diaries to organise the file, but once the initial set up is done, it's very easy to maintain.

So then ... deep breaths in ... and out...! Stay calm whenever possible, and play a pro-active role in getting what you need from the people that can provide it, without driving them (and more importantly - yourself) mad! Good luck!

Lia Moran

## Half PINNT Fun ... Kids' Zone

We've received very little feedback about the Kids' Zone supplement that has been included with the last couple of editions of Online.

If we are to continue producing this we need to be sure that enough of you are enjoying this in order to justify the time that goes into producing it ... so, if you like it, let us know! Better still, send us your contribution – we'd love to hear your story along with your jokes to make us giggle.

Don't leave it to someone else to contact us – we want to hear from you! So, get your brother, sister or best friend to help you and write to Drippy Bear, c/o PINNT, PO Box 3126, Christchurch, Dorset, BH23 2XS.

# REFLECTIONS

by Joy Field SRN Dipl MBE

**O**n April 20th 2007 I retire after more than 40 years in nursing.

Since January 1976 I have been involved in the care of patients requiring complex nutritional support by both the enteral and parenteral route – my appetite being whetted by the first patient I encountered, desperately ill and needing parenteral nutrition, a treatment I knew little about at that time.

Over the years I have been privileged to work with some wonderful and dynamic colleagues, both medical and surgical, nursing and dietetic. I have cared for some incredibly courageous patients and I have to say that I have thoroughly enjoyed my nursing career. I was approached by the editor of Online (one of my existing HPN patients) to write a piece reflecting on what changes I have seen over the last 30 years in relation to PN.

As already mentioned, my first contact with inpatient PN came in 1976 - things were very different and more difficult in these early days. We did not have the 'all in one' bags of feed whose use did not become widespread until the early 1980s in the UK. Certainly in my hospital there were few, if any, volumetric pumps to deliver the feed. The central venous catheters were predominantly single lumen and there were no commercially made occlusive dressings to cover the insertion site.

A patient requiring PN was nursed on a general ward, and had a single lumen catheter, attached to which was a rack of connectors (traffic lights) to which the five or six giving sets administering the feed were connected. The rate of the multiple fluids was controlled simply by the roller clamps on the giving sets and by adjusting and readjusting the height of the drip stands on which all the bags and bottles hung.

The fluids were of differing densities: 50% dextrose, saline, amino acids and fat emulsion, and they either ran too fast, too slow or they stopped. The bottle containing the light sensitive vitamins had to be covered to prevent them degrading. We used tin foil, bought from the local shop, and wrapped both the bottle and the giving set, leaving a small gap by the drip chamber to ensure the fluid was still running. It was a tedious job adjusting and readjusting the roller clamps, and all of this increased the risks of errors and complications, particularly metabolic complications. As for dressing the lines, the insertion site was covered by either an Elastoplast or Slek dressing. Believe it or not, patients did recover.



Today we are much more experienced. We have "all in one" bags of feed (up to 4 litres in volume if needed), with everything compounded in sterile production areas in pharmacy. These are used routinely for inpatients. We have

standard formulas with specific calorie, nitrogen and electrolyte components suitable for most patients. Tailor-made more complex formulas can be produced for specific patients and some bags of feed can be kept out of the fridge and on the shelf (until mixed together) – useful as emergency back-up, for weekends and bank holidays, when new patients could arrive.

In addition we have multi-lumen catheters which have enabled "traffic lights" to be relegated to the bin, occlusive dressings and adequate supplies of volumetric pumps with in-built alarm systems not only to alert you to problems, but to safely deliver specific amounts hourly.

Patients are now often nursed by staff experienced in PN and the odd clinical nutrition unit has emerged, one of which I personally commissioned and opened on January 1st 1998 in my own trust.

Much work has been done by the National Nurses' Nutrition Group (NNNG), myself a founder member, and the King's Fund Centre, to set protocols and standards for the care of central venous catheters and PN, all aimed at reducing complications and costs and improving the patient's experience.

Nutrition Support Teams (NSTs) have been encouraged to develop and published literature has shown that these teams serve to raise standards, improve patient selection and enable more appropriate treatments to be given, thus reducing complications and costs to individual trusts. Specialist nurses have played a vital role as members of NSTs. Sadly, of late, some short-sighted trusts have viewed these specialists as an expensive waste and as such posts have been cut and jobs lost, I believe to the detriment of patient care.

## Home Parenteral Nutrition

I met and discharged my first patient requiring HPN in 1984. I felt terrified as he left the 'safety' of the hospital ward – the responsibility for his care felt enormous.

I was fortunate in 1983 to be awarded a travel scholarship for my first published paper which discussed the 'emotional aspects of PN'. With the scholarship I chose to visit Prof Jeejeebhoy in Toronto. I also spent time in Sandiago, California. I wanted to see how these centres managed HPN. I had a sneaky feeling that it would not be long before I would be involved with it. In Toronto I met a lady who had been on HPN for ten years and learnt a great deal of practical things from her. I also came across Portacaths (implantable devices) being used for the first time.



I had only been back in Nottingham for one month when the first of what was to become many HPN patients was referred to our NST. How very different and challenging it was then in order to discharge this man, having taught him the management of HPN and allowed him to use the ward as a "hotel" for a week to help his confidence. In order to obtain a fridge for him I had to personally approach a number of charitable organisations and plead his case, eventually being successful and getting a large domestic fridge. The solid large hospital dressing trolley he used for sterile procedures was drawn from an old store in the bowels of the hospital. His pump and stand were hospital issue from my ward stock, thus depleting my limited stock of in-house pumps by one. All his ancillary items also came from my ward stock; each week I had to package them up, hoping I had not forgotten anything, and then book a taxi to deliver them, and his feed, to his home.

Each night after work I was on call in case he had a problem. I was often phoned at 1 or 2 am, got into my car and drove to his home to sort out the problem, usually arriving back a couple of hours before the start of my own working day. There were no on call, telephone or fuel payments – it was simply part of the role of caring for complex home patients at that time. There were no homecare companies to take the administrative pressure off our shoulders and ease transfer home in those early days.

## Today

Most of the administrative side of discharging a person on HPN has been taken over by homecare companies, several of which have emerged during the last 15 or so years. Once the list is

written and faxed to them the patient's ancillaries and equipment are delivered via the company to the patient's home and stock levels are monitored and maintained by them. Pump maintenance and back up forms part of the package. In addition there is a 24 hour phone helpline, thus removing the need for on calls by hospital staff. Most companies also employ qualified specially trained nursing staff who can assist in either staff or patient training and also in the patient's actual homecare if needed, thus enabling early discharge from hospital to be achieved. Of course all of this comes at a price, but having worked with and without a homecare company I know which system works best – clearly the former.

Support groups such as PINNT have done a vast amount of campaigning for patients' rights - they also offer sound holiday advice. I can remember getting the chairman of an airline company out of a meeting whilst struggling to get a patient on holiday with their supplies and "hitting a brick wall" with his staff – of course I succeeded but the time it took, took me away from other duties. PINNT have also been instrumental in identifying problems associated with standard hospital equipment, ie pumps and stands, in the home. Now, due to PINNT's and LITRE's efforts, many patients have portable pumps, back packs and stands, thus allowing a greater level of freedom than ever before.

## The Future

As to the future, I am sure there will be many more innovations to help improve the quality of life for people requiring complex nutritional support. I hope NSTs and units will grow and flourish and I hope the trend to reduce specialist nurse posts ceases.

I feel sad on one level that I will not be part of the future, but feel very privileged to have been part of such an exciting and evolving therapy. I hope that 'new blood' will take up the mantle and continue to strive and improve the lives of these special patients.



**Ed replies:** Although Joy is 'hanging up her hat' I know that she'd like to stay in touch with the field of nutrition and would love to hear from her patients and medical colleagues, both past and present, so please send your letters and emails for Joy c/o Barbara Berry (see Contact Us section) and I will forward them on to her.

# "THE COLDCHAIN, WHAT'S ALL THAT ABOUT?"

## A GUIDE TO THE STORAGE AND TRANSPORT OF REFRIGERATED PARENTERAL NUTRITION SOLUTIONS

by Andy K Low MRPharmS DipClinPharm. Director, Willow Healthcare Services Ltd

### Introduction

This article has been written to provide information about why all-in-one Parenteral Nutrition ("PN") solutions are kept refrigerated (i.e. kept between 2 and 8 degrees Centigrade), how the coldchain works, and is intended to answer some common questions that arise.

## WHY ARE PARENTERAL NUTRITION SOLUTIONS KEPT REFRIGERATED?

There are two possible reasons, these are:

### 1. To maximise Physicochemical stability

PN fluids are usually highly complex mixtures of chemicals as has been well described in Rebecca White's article "Recipe for Life" in the October issue of Online. These can react with each other in a number of ways. Whilst problems such as precipitation (the formation of solid particulates within a solution) are prevented by ensuring that a stable formulation is chosen prior to manufacture, other types of reaction happen only slowly, leading to gradual degradation of certain nutrients over time. These types of reactions can be slowed (and thus shelf lives lengthened) by refrigeration. Examples include:



**Fat emulsion instability.** We are familiar with what happens to milk over time and those PN regimens containing fat or lipid are subject to the same degradative process. PN bags containing fat (an example of which is shown in figure 1 below) are thus emulsions of fat globules suspended in water and will break down over time, leading to separation of the emulsion layers. Even kept refrigerated the presence of lipid will usually limit the shelf life of the bag, typically to 30 days or less.



Figure 1. PN Bag containing fat as an emulsion



**Vitamin stability.** Vitamins are inherently unstable in solution; they degrade and lose their potency over time. For this reason the manufacturers provide vitamin preparations such as Cernevit and Solivito as freeze dried powders. If these are being added to the bag they are reconstituted (i.e. dissolved in water) during the compounding process. Those regimens containing vitamins will have their shelf lives limited by the progressive deterioration of the vitamins, a process which refrigeration again will slow down.

### 2. To maximise Microbiological stability.

PN fluids are obviously intended for intravenous use, thus the avoidance of microbiological contamination is a critical priority for all compounders of such solutions. The entire compounding process (from facility design and operation to operator training) is designed with this in mind. However to minimise the risk to the patient even further the additional precaution of refrigeration is placed upon the storage conditions of the product.



Andy Low

Thus, if the worst were to happen and a micro-organism was to be introduced into the bag the potential for harm would be minimised by the fact that at refrigerated temperatures the rate of growth of the organism(s) would be significantly slower.

It is important to note that whilst the bulk of the storage period for PN solutions will usually be at 2 to 8 C this is invariably supplemented by a 24 hour period at room temperature to allow for warming and administration, which will have been taken into account when the shelf life is assigned.

### Are all PN bags stored in a fridge?

At this point it is relevant to mention that some PN solutions can be stored at room temperature. An example is those bags presented with multiple compartments in which the amino acid, glucose and lipid fluids are kept separate until just before administration. They avoid the aforementioned problems because:



The lipid is kept separate from the water based components during storage.



They do not contain vitamins

Whilst their stability at room temperature is a great advantage they are "off the shelf" products and have thus not been tailored to meet individuals' needs. This, together with the fact that they do not contain vitamins or trace elements (i.e. they are not All-in-one bags) limits their usefulness for home treatment.



### How does the Coldchain need to work?

Clearly, the coldchain is put in place to ensure that from just after compounding to the warming up period just before administration each PN bag requiring refrigeration is both stored and transported between 2 and 8 C.

This requires controlled refrigeration facilities wherever the product will be stored as well as a validated system of maintaining the temperature during transport, typically using a coolbox system that has been validated to prove its effectiveness. The term "coolbox system" is used here to comprise both the materials used (coolbox, icepacks etc) as well as the conditions under which they are used (e.g. location and starting temperature of the icepacks), as defined by the protocol that comes from the validation process.

When using coolboxes the product must start chilled, be packed into the coolbox with icepacks and transported within the validated limits of time and temperature that apply.

### Why are refrigerated vans sometimes used?



Figure 2. Van with roof mounted refrigeration unit

Vans equipped with chiller units are sometimes used. However, in the most commonly encountered vehicles of this type the chiller unit is driven by the vehicle engine. Thus when the vehicle stops the temperature is no longer controlled. Unless the loading area in the vehicle can itself be validated to prove that whenever this happens it does not go above 8C these vehicles cannot provide the cold chain on their own. They may however have some use in extending the validation period of the coolbox by reducing the average temperature it is exposed to.

### How are coolbox systems validated?

All coolbox systems require validation to prove that they can cope with what they are expected to do. There follows an example of how a coolbox system might be validated dividing the process into four stages:

**1. Planning.** A requirements specification is drawn up which details the required minimum length of time the coolbox needs to be validated for as well as the expected minimum and maximum temperatures it will be exposed to. Details of the anticipated product load for the coolbox (including the type of product, mass/volume and starting temperature) will also be defined. An advantage of PN bags is as they comprise relatively large volumes of fluid, once chilled they require considerable energy to heat up compared to, for example, prefilled syringes.

**2. Material Specification.** A coolbox type and configuration is chosen. This would include:



Coolbox description. Size, type and thickness of material, starting temperature etc.



Description of inserts. These include icepacks and sometimes spacer materials and must be defined in terms of size, make, starting temperature, number and location within the coolbox.

**3. Testing.**

The proposed coolbox is loaded with sample product and associated inserts as previously defined and a device is inserted to continuously monitor the temperature inside the box. It is then exposed to a series of exterior temperatures, most easily done using controlled temperature environments.

**4. Review and generation of packing protocol.**

The results of testing will be used to determine how long the coolbox system is validated for. As this is different depending on the exterior temperature, this may result in more than one system, "summer" and "winter" versions (a summer version might comprise only frozen icepacks for example whereas a winter version might be a mix of frozen and chilled). However, the extra complexity of managing more than one system means that a single version that can be used all year round is most popular.

In conclusion, in order to have confidence in a coolbox system it is necessary to manage and control many different factors, from the materials used to the starting temperature of the icepacks.

### What happens if PN solutions warm above 8 degrees centigrade (or cool below 2)?

This could happen because:



The exterior temperature that the coolbox is exposed to is outside of the temperature the boxes were validated at (e.g. boxes validated at an average temperature of 30 C experience an average temperature of 32 C)



The duration of transit exceeds the time the boxes were validated for (e.g. boxes validated for 16 hours are used for longer)

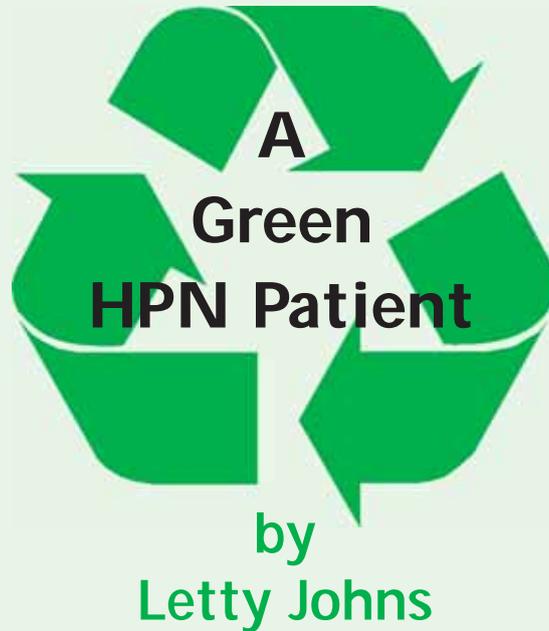
To determine the effect on the product we must again consider how the physiochemical and microbiological stability might be affected. This is outlined in the table below:

	Effect on physiochemical stability	Effect on microbiological stability
Fluid temperature exceeds 8 C	Potential for increased chemical degradation of nutrients	Theoretical increased risk of sterility failure
Fluid temperature is lower than 2 C	Potential for freezing, resulting in significant chemical changes to the contents of the bag such as cracking of lipid emulsions	None

Table 1. Examples of the effects of storage of PN outside recommended temperatures

Don't get alarmed - I am not going mouldy or feeling off-colour; I am talking about being environmentally friendly 'green'. I have been on HPN for nine years and I am unable to throw away anything that can be of use. By this I mean our dressing packs. I have the pack recommended by the Hope Hospital. With every feed I use two packs, one to put myself on and one to take myself off. I do not need all they contain each time so over the years I have found uses for the 'left-overs'. I put all the cotton wool balls in one bag, the paper squares in another bag and the soft gauze into a third bag. During my time on HPN I have 'acquired' four grandchildren and my daughter and daughter-in-law have found these supplies very useful. The paper squares were put on the changing mats under the babies, the cotton wool balls were used to clean the babies' bottoms after dipping them in water (the cotton wool, not baby's bottom) and then baby was dried with the soft gauze. Now my grandchildren are all out of nappies, but I still collect whatever I have not used in my dressing pack and if I know of anyone with a baby I pass the bags on to them.

I use the paper towels from the packs to clean windows or wipe up any spillages etc. instead of kitchen roll. The bags of cotton wool are given to anyone who needs to remove make-up etc. The unused galley pots are kept for holding water when the grandchildren want to paint and I also send them to their school and the class teacher finds them useful for painting etc. After every feed, there are eight blue plastic tweezers and these go into the plastic recycling sack. My husband cuts off the plastic handle at the top of the bag that holds my feed and that also goes into the plastic recycling bag. It sounds as though we are obsessed with recycling but after every feed it varies as to what is left over and it seems such a waste to throw away the cotton wool balls etc. that have not been used.



Maybe I am 'green' because of my name - Lettice (pronounced Letteece) but often pronounced Lettuce (as salad). My school uniform was green too and in the 1950s Girl comic had a character in it called 'Lettuce Leaf - the Greenest Girl in School'. So enough said - that is where I get my sense of humour from but I can give as good as I get.

I have just read the January Online and the piece on the front page about being a realist could have been written by me as it is exactly the way I cope. Nobody wants to know you if you grumble day-in, day-out. I would rather keep my family and friends by being cheerful. My poor husband is the only person who sees the other side of me and he knows how to cope with that now.

I am interested in family history and have been researching ancestors but I am also writing a little 'information book' about them and going on to tell the tale of my life and what I did as a child, then getting married and so on. My children don't want to listen now but in the future I am sure they will find it interesting and it will prove to them that Mum and Dad, aka Gran and Gramps, weren't always old and unwell. We did have quite an exciting life!

**Ed replies:** Thanks for this Letty - PINNT strongly advocate recycling. However, it might be worth asking whether there is a dressing pack that is more suited to your needs - even though you're recycling, it's a pity to have so much stuff you do not use.

## THE COLDCHAIN continued from page 9

Usage of these complex products outside of the recommended storage conditions thus has the potential to present an additional risk to the user. Quantification of the degree of risk needs to take into account a number of factors. As patient safety is clearly an over-riding concern, wherever there is doubt as to the condition of the product further advice should be sought. A thorough pharmaceutical assessment of the situation will clarify whether or not there is any cause for concern.

### *How might you suspect a problem with the temperature your bags have been stored at?*

The most likely way of noticing is if the bags are warmer (or colder) than usual to the touch.

### *How can you be reassured?*

An approximation of the temperature can be made by placing a thermometer between two bags whilst they are in the coolbox or refrigerator and leaving it for 15 minutes. This is the best non-invasive way of assessing the likely temperature of the fluid.



# Introducing a New Member of the Editorial Board

Hi. My name is Lia Moran and I'm a chocoholic (Minstrel's in particular!). But seriously, I'm 33 years old, and I'm the very proud mother and carer of Lucas, who's six. I'm very flattered to have been asked to join PINNT's editorial board, with a view to providing some input into Half PINNT issues. Other than caring for Lucas, I am also a writer - so hopefully I'll be reasonably qualified for the honour of writing regularly about our ongoing ups and downs!

Lucas was born six weeks prematurely with gastroschisis, where unfortunately, almost all of his small bowel had protruded through his abdominal wall, making repair almost impossible. He subsequently spent the first eight months of his life in Birmingham Children's Hospital and Great Ormond Street Hospital, after losing all but 10% of his small bowel. He was in and out of intensive care during that time, and succumbed to

numerous life-threatening infections and multiple organ problems.

He's always been on TPN,



and has recently had a gastrostomy button fitted, and so he is now fed enterally as well (he also eats 'normally' - scrambled egg is his favourite). In fact, he's doing so much better than any of us ever imagined he would, and we are currently trying a new regime of the HPN just three nights a week, and the enteral milk for five nights. It's all going okay so far,

although he can't achieve this if he's unwell with a cold etc., as he tends to become hypoglycaemic. Additionally, his growth is

still very slow indeed, making him far smaller than his peers.

All that said though, Lucas is a happy-chappy indeed. He enjoys school, and lives life to the full, despite tiring very quickly and easily - especially if there's any walking involved. Up until now, he's always been very accepting of his condition, but we've found that the more nights of 'freedom' he

enjoys off his pumps, the more he wants, and he's becoming a little resentful of his Hickman line and button lately.

**I think it would be very interesting to hear more from 'the kids' who deal with the impact of artificial nutrition on a daily basis, and also from their siblings too. With that in mind, I'll be interviewing Lucas about how he copes with it all. From my perspective, I'd be very interested to hear more from other parents with children on HPN or enteral feeds, and also from teenagers as well, so that I have some idea of the challenges that Lucas might face as he grows older. It would also be great to hear what the PINNT and Half PINNT readers want to know more about, so drop a line to the usual place with your letters and ideas please.**

## **What else should you do?**

If you have any concerns at all contact your homecare company or referral unit for advice. On no account use products that you think may have been stored outside their conditions without doing this first.

## **In conclusion**

Much time, effort and expense is devoted to ensuring the success of the cold chain in getting PN bags to the end users fit for use. Careful packaging, design and thorough validation will continue to play a crucial role in the face of our increasingly challenging climate, both here in the UK and also abroad.

## **Acknowledgement:**

I would like to thank Professor Mike Allwood for his assistance in the writing of this article.

*Andy trained as a Hospital Pharmacist and spent the early part of his career within the NHS managing Clinical Pharmacy Services in Romford, Essex. His involvement in*

*homecare began in 1995 when he joined Clinovia (then known as Caremark) and spent 9 years there, the latter 5 years as Technical Director.*

*After leaving Clinovia in 2004 he set up Willow Pharmatech, a company specialising in Pharmaceutical Consultancy including the design and construction of Aseptic Manufacturing facilities.*

*In 2005 he established a new Homecare Company (Willow Healthcare Services) with fellow Director Mo Rahman.*

**Ed Replies:** If you have any questions for Andy, please send them to PINNT, PO Box 3126, Christchurch, Dorset, BH23 2XS, or email [PINNT@dial.pipex.com](mailto:PINNT@dial.pipex.com) and put 'A. Low, Coldchain' in the subject heading. Please also remember that expert pharmaceutical advice should be available from a member of your nutrition team.

# READERS'



THANK YOU for giving me the incentive to contact you about my experiences with my gastrostomy and bolus feeds with Nutrison during the day. Just over a year ago I started to find that I couldn't eat or drink without coughing. This gradually got worse until I was rushed into hospital and had a gastrostomy in May, just before my birthday (what a birthday present!).

At first I was coping quite well, but as time has passed and I seem to be improving very slowly, I have found it harder. I used to enjoy my food so much. My husband, son and daughter have been very supportive and we have had some laughs along the way. It is lucky that the dining room is painted cream as it has been sprayed with Nutrison (we also had to clean it off some homework and apologise for its appearance). My son wanted to clear the air from a syringe full of Nutrison by pointing it at the ceiling like he had seen on television.

One problem I have is that there is no gastrostomy clinic that I know of. The district nurses in my doctor's surgery are rushed off their feet and I don't like to bother them with most of the questions I would like to ask. When I first had to turn my PEG I wanted someone with me. The district nurse who came had no idea how to do it and we sat there reading a leaflet I had, saying to each other "do you think it's this way or that way?" We managed it! The nutritionist and speech therapist ring up now and again to see how I'm doing. Thank goodness the nutritionist mentioned PINNT.

I also have the problem that everything seems to be just the wrong (or right depending on how you look at it) height for my PEG i.e. the backs of seats on buses if they stop suddenly, shopping trolleys and the conveyer belts at the checkouts. As I am just about 5ft 3ins tall this may account for some of these. I wonder if others have this problem.

My goals for the future are to get out more – a job will definitely help – and to get away for a holiday. I left my job at a primary school when the ease at which I could choke and the amount of time off I had to take became embarrassing. I have not been able to find another job yet and I am finding it difficult. Ian Swain's article 'How to Get Back to Work in Ten Easy Steps' in the October 2006 edition of Online is helpful. I would love to have a holiday, maybe abroad, and your information on this has been very informative. 'Top Tips' and answers for questions of a practical nature would be very useful.

Rosemary Winchester

**Ed replies:** Thanks for sharing your story with us Rosemary. If you have any 'Top Tips' for Rosemary about going on holiday or getting back to work, please write in and we'll print them in the next edition of Online.

FOLLOWING RADICAL RADIOTHERAPY in 1990 due to cervical cancer I suffered from severe malnutrition which has meant that for the last 6½ years I have needed HPN six nights a week for a minimum of ten hours per night.

The positive aspects of HPN are that it's life supporting – and I get to spend quite a long time in bed! However I do have to make a lot of trips to the toilet during the night due to loose bowels and this means that my sleep is broken every two to three hours so I do get very tired. My main concern is that I don't get line infections – I've had three and that's enough!

My life was turned upside down in 1990 when I was diagnosed with cervical cancer and the radical radiotherapy treatment gradually sent me into intestinal failure. However, I am very well supported by St Marks hospital and attend for four monthly check-ups. The best piece of advice I could pass on to

others came from my team at St Marks – don't let HPN run your life.

Alongside my HPN, I need to try and make up about 500 calories, 4 days a week, but my appetite seems to be shrinking as time goes on and I am rather underweight. In general, living on artificial nutrition isn't a problem but in my case with loose bowels I can't go out and about much before 11 am whilst my system settles down from the nightly two litre intake of liquid. Eating out also requires access to toilet facilities as eating stimulates my bowels.

I am 72 so my days are free for home life and family outings and I manage to take short holidays in the UK – usually 3-7 days. My goals for the future are simple – to keep active and healthy.

Phillipa Stower

HELLO EVERYONE. I became a member of PINNT in October 2005, after meeting Carolyn Wheatley at a seminar given by Fresenius to educate their staff on what their service means to us "the customer". Carolyn made me realise just how important it is for people in a similar predicament to try and help each other by sharing knowledge and experience.

Until September 1996 I was able to, and did, eat very well, which was probably the reason for my original problem - acid reflux. In 1994 I started getting severe acid reflux with extremely bad heartburn. My GP put me on medication which relieved the acid reflux very effectively until the middle of 1995. I had an endoscopy which revealed that I had severe reflux oesophagitis and my GP referred me to an upper

gastrointestinal consultant in Leeds, West Yorkshire, where I live. At the end of 1995 the hospital consultant did another endoscopy and discovered I had Barrette's Oesophagus which is a pre-malignant change in the oesophageal lining. The consultant advised anti-reflux surgery called Nissen Fundoplication to control the reflux and stop the Barrette's disease from getting worse.

# EXPERIENCES



I had the keyhole

surgery on the 23rd September 1996, and on 25th September the consultant said it was okay for me to begin eating a soft diet. This is when I realised my troubles had really begun. The first time I tried to eat, I experienced severe chest pain and a feeling that the food was stuck. I tried to wash it down with a drink but the pain immediately got much worse. When the pain had subsided, the nursing staff on the ward said not to eat but to only take drinks until the doctors did their ward rounds. To my horror I got the bad pain again when I tried to drink water. The consultant did an endoscopy and dilatation of my oesophagus but even after two more dilatations, the swallowing problem continued.

Over the coming months I experienced weight loss at the rate of one stone per month and received no nutritional advice or help from the hospital despite repeated attempts by myself and my GP to bring it to the hospital consultant's attention. I thought I was going to die, because at this time I

did not know enteral feeding even existed, let alone that it was possible to have it at home.

In June 1997 I underwent surgery to reverse the previous anti-reflux surgery because the consultant said it was the only way forward. After the reversal surgery I still could not swallow food and it was still very difficult to swallow liquids. Also my severe reflux had returned, so I now had the old problem back as well as the swallowing problem. In the middle of July 1997, after losing about eight stones in weight, I was finally referred to the hospital dietitian as an inpatient. During my stay in hospital I was given enteral feeding through a naso-gastric feeding tube. My weight immediately began to rise and I felt much better after just a few days. In the middle of August I was discharged from hospital but the doctors removed the feeding tube and sent me home without the enteral feed. My weight began to drop again and my consultant first tried to blame it on diabetes, but the tests proved negative. Then he said I may be losing weight due to Adult Coeliac disease, but again tests proved negative. At least this time I had the

benefit of frequent visits to the hospital dietetics department. In December 1997 the hospital dietitian advised my consultant that I should be given home enteral feeding without delay. So once again a naso-gastric feeding tube was inserted, and after a week in hospital I was discharged home with the feeding tube in place, a feeding pump and feed for home enteral feeding. In June 1998 my consultant discussed replacing the naso-gastric feeding tube with a gastrostomy feeding tube and a re-do of the reflux surgery. I had the surgery in September 1998 but the consultant had inserted a jejunostomy feeding tube instead of a gastrostomy tube. He did this without discussing it with me first. I now feel it is very important for a patient to make sure that the surgery they receive is the one discussed in clinic and not one the consultant decides to do as an afterthought. Although all feeding tubes have their problems, each one has different problems and risks. I think that we should be made aware of just what we are getting into before allowing surgeons to perform procedures on us.

The jejunostomy tube that was inserted was secured by stitching it to my flesh. These stitches kept coming out and had to be replaced every few days. The hospital doctors said that there was no other way of securing jejunostomy tubes and that I would have to get used to it. I spent just 20 minutes searching the internet for an alternative and found the MIC jejunostomy tube that is secured inside by a Dacron cuff that adheres to the flesh. I informed the consultant of the MIC jejunostomy tube and he said he had not heard of it and that it must be new (it had been used elsewhere for quite some time). He said he did not know where to get one from, so I gave him the supplier's address. He eventually agreed to fit one for me. Even though it still has its problems and risks, I have found it to be much better than the previous one. I think it is always worth looking for a solution oneself, because you cannot always rely on your hospital consultant to be looking for one.

In 2003 the hospital pain team fitted me with a spinal cord stimulator to help reduce the swallowing pain. However, the swallowing

improvements were small and I still spend about 15 hours per day on enteral feed. It was still well worth doing because I can now eat very small amounts of food, whereas before, I could eat virtually nothing. I have had several problems with the spinal cord stimulator breaking down, but after travelling to Middlesbrough's James Cook hospital in June 2006, where a plated electrode was installed onto my spine, it now seems to be still working well and I am now eating tiny amounts of normal food again. This will never be enough for me to stop enteral feeding but it is good to just taste real food again.

It is important to realise that without enteral feeding I would not be alive today and that my world has not completely stopped going round because of it. Enteral feeding is a positive, not a negative therapy, and even though I am unable to work there are still many other things I can do.

Gordon  
Beaumont

# POST ROOM



My Baxter 6060 has now been replaced with a new portable pump. I was **told** I would like it, and being fair, I have given it a fair assessment. It is bulkier than my previous pump and dare I say this, it's really noisy. My sleep is now disturbed as is that of my partner. I was prepared for a new pump having different functionality but I truly believe this pump is not conducive to a sound night's sleep. I've broached the subject with the homecare supplier but they do not seem keen to allow me to trial one of the other pumps. Any suggestions?

Ed replies: Thank you for your letter. We have received several calls on the same subject. We suggest that you contact your hospital/unit/centre and speak to the people who provide your care and inform them of your personal situation. The homecare supplier is carrying out the wishes of your centre and cannot change the product without their consent. Tell your unit that you obviously wish to use a pump that is clinically safe and effective but are finding the disruption to your usual sleep pattern unacceptable. They may need to assess each case individually to ensure patient satisfaction. It may well be the case that if you try alternatives your preference may not be as you thought. If you can try suitable alternatives you should be allowed to use the clinically safe pump that is right for you.

LITRE have published their conclusion following their meeting to appraise the replacement portable pumps currently on the market. You can access this report by logging on to [www.pinnt.com/downloads/litre\\_pn\\_pump\\_assessment.pdf](http://www.pinnt.com/downloads/litre_pn_pump_assessment.pdf) or by contacting Justine (number shown in the Contact Us section) for a copy.

*I am writing with regard to the letter from Lynne in the January edition of Online, regarding the issue of rechargeable batteries for portable pumps. We at LITRE are strongly urging the manufacturers to do all they can to facilitate long-life rechargeable batteries that are lightweight. At the moment it does not appear to be possible to have both; extended battery life can only be delivered with a heavy battery. In November 2006 LITRE published its 'Assessment of Ambulatory Pumps for Parenteral Nutrition', and I have copied the relevant paragraph below:*

#### 'Environmental Issues

While LITRE are conscious that patients like the option of dry cell back-up with their pump we would seriously ask people to consider smaller lightweight rechargeable power options with extended life to reduce the amount of batteries that are used, thus saving further detriment to the planet. Dry cell batteries should be for short term or emergency use only.'

The battery capabilities of the four pumps evaluated can be found in the report, which can be found on the PINNT website: [www.pinnt.com](http://www.pinnt.com)

LITRE will continue to work with the manufacturers to ensure that patients using a portable pump have the best battery technology currently available which is also suitable to their circumstances.

Justine Bayes  
LITRE Chairman

Thank you so much for sending the booking form for the 20th Anniversary weekend. It certainly looks good, I will be sending my form off soon. It will be nice to meet other PINNT members. Hopefully as many people as you can accommodate will attend to say well done for all the hard work that has obviously gone into putting such a good event together.

RB

PINNT needs your help - have you travelled to the USA within the last 12 months? If so, please tell us whether you have had any problems taking your parenteral nutrition into the country. We need to know if you took the feeds with you on the plane or whether your homecare provider had them shipped out for you. Any information will be gratefully received.

PINNT

I felt that I just had to write and thank you for the front page article in the January 2007 edition of Online. It was so good. I could have written it about me. I felt that I wanted to show it to all my friends just to let them know how I really feel and what lies behind the jolly "I'm fine - look at me" side I always try to show.

I have recently been involved in a car accident when a car ran into the back of my car and I had to be cut out of the car (just like an episode from Casualty). I ended up at my nearest hospital and was amazed that the staff at this hospital had no idea at all about TPN or the sterile procedures needed when dealing with this. I kept asking them to contact St Marks, Harrow, who knew all about me and my condition, but they seemed to not want to do this. My husband brought my TPN to the hospital every night for me and I put it on using my normal sterile procedure.

I had constant high temperatures and worried about having an infection in my line. When I told the doctor, he bent down and pulled my dressing off my Hickman site (no gloves or spray), looked at the site and declared "that is clean - no infection there". I then had to explain that the infection could be in the line and that blood had to be taken from the line and a culture grown over a few days to check if the line was clear. Thank goodness another doctor finally contacted St Marks, and cultures were taken.

Do you think it would be possible to have some sort of card printed that gives all the relevant TPN information and the contact numbers of hospitals and nutrition teams who deal with us and our TPN, and also states that sterile procedures should be used when dealing with lines?

Sorry if I have rambled on but I felt very frightened by the lack of knowledge and reluctance by another hospital to contact my TPN hospital and listen to me about my body and its needs.

Thanks for all you do. I really love receiving Online and it really gives me a buzz knowing that my life and feelings about TPN are shared by others.

Jean Beard

# POST ROOM

I have recently joined PINNT and would like a restaurant card. I have just started on overnight pump feeds. I have a PEG and I am having a few problems with my feed leaking out of the medicine port and wondered if anyone else had this problem and how they deal with it? Any help would be gratefully received.

Wendy Lait

**Ed replies:** If you have any suggestions for Wendy please send them c/o Barbara Berry (see Contact Us section) and I will forward them on.

Thanks for sending me the past three copies of Online when I joined PINNT in October. I have read through them and found them to be very helpful indeed. After having a gastrostomy in August because of oesophageal dysmotility, I felt as if I was the only person suffering from this problem at the age of 42. My illness started about 15 months previous to this when I began to have swallowing problems. Over the next few months I went to and from the hospital almost every week. During this time I lost six stones in weight and became very weak and frail. I was on Ensure but eventually I couldn't even swallow that, so I had to have the gastrostomy.

After leaving hospital I felt like my life was finished - unable to go anywhere and do anything because of having to feed - and as for holidays, I thought they would be a definite 'No'. But after reading Online and all your other members' letters it gave me a whole new outlook on life, so much so that I got in touch with the excellent dietetic team at Wrexham Maelor Hospital to change my regime from feeding overnight with a 1000mls of Jevity Plus which myself or my wife found very hard to deal with, to feeding twice a day with 500mls. The change made all the difference to our lives.

Also I am now looking at booking a holiday - something we haven't been able to do for two years. I once again ran this by the dietetic team and they gave me all the support they could. They have changed my pump from the Patroll to the more portable Clearstar which looks good and is made for travelling, so me and the family are really looking forward to 2007 and the opportunity of going away. Could you please send me all the leaflets you have about going abroad and anything else you have which would help me through what I can imagine is the difficult process of getting everything right. Thanks for producing this great magazine - it's helped me more than you could imagine.

Steve Hodgetts

Now the NHS are setting up centres of excellence, patients often have to travel many miles for treatment, and I wonder whether anyone can advise me whether or not it is possible to claim travelling expenses in these circumstances, and if so, who I should contact for reimbursement? My daughter has had pioneering surgery for her underlying condition and my feelings are that because the NHS could not provide the treatment needed locally, surely the cost of ongoing outpatient treatment, and travel, was taken into account when the Primary Care Trust funded the operation.

My daughter currently gets Disability Living Allowance at the middle rate and also incapacity benefit and the only other thing she has ever claimed for are free drugs. I know there could be more that she is entitled to but she feels very strongly about people knowing her personal details. My argument is that as the Primary Care Trust should have taken travel expenses into account when funding the surgery, then surely the matter of reimbursement should have no bearing on what benefits she is on.

On paper, hospitals of excellence are a good idea but we have found that there doesn't seem to be any help regarding reasonably priced accommodation for relatives who need to be able to visit the patient. It also seems that when a patient needs to keep outpatient appointments after their surgery, there is no help towards travelling costs unless the patient is willing to declare all their personal details.

Jan

My daughter Stella is 26 years old and has a rare syndrome called Hypomelanosis of Ito. She has learning disability, is partially deaf, blind and has deformities of her mouth and throat which made it very difficult for her to swallow as a child and from the age of nine she hasn't been able to swallow at all. She also has severe sleep apnoea.

I would like to know whether there is anyone else out there who has had a gastrostomy long-term (Stella has had hers for over 17 years) and whether they have had any problems which may be due to it being so old? Also, is there anyone else who cannot have the PEG procedure like Stella, who if she ever needed a new "hole" made would have to have surgery (as she did originally before they used the PEG procedure)?

We recently had a bit of a crisis with Stella as I couldn't get her replacement Mik-Key into her tummy as it just kept bending; we've since found that if we insert a stiffener down the centre and allow Stella to do it herself (I suppose she relaxes more doing it herself) it goes in fine. Has anyone else had problems inserting theirs/their child's Mik-Key and what have they found helps? I'm concerned that it may happen again and that even Stella may not be able to get the new tube in.

The only back up I have is the PEG nurse who only works 9-5, or the A&E at the hospital where she's based 40 minutes away (or more in rush-hour). The District Nursing manager was looking into offering training for replacing PEGs to her nurses (if they volunteered) as a response to my putting pressure on the local Chief Executive of the Health Trust to provide more support for people in the community with PEGs, but since she heard of our episode she's ditched the idea! I'd be interested in anyone's thoughts as to what I should expect, and therefore campaign for, from my local health authority.

Val Church

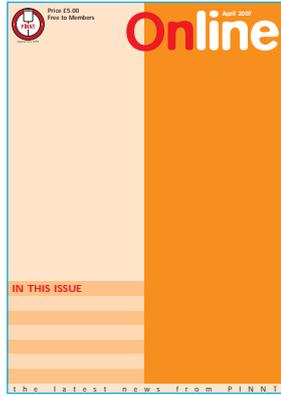
**Ed replies:** Please send your comments for Val c/o Barbara Berry (see the Contact Us section) and I will forward them on to her.

Following on from the article 'Can I Swim with a Central Line' in the January edition of Online, the advice I was given by my hospital when I started on HPN four years ago was not to swim. However, after a year I was tempted into the pool, and as my local pool does not have a 'deep end' my intention was to just walk in the water, keeping my line above the water - but it was so good to be in the swimming pool once again that soon I was swimming properly with everyone else and I enjoyed it so much that I stayed in for three hours. I am happy to report that I have now been swimming regularly for three years with no line infection connected to my swimming. I do take precautions to keep my line totally dry, using six Tegaderm dressings in all to completely cover the exit site and the line. I have recently had my line replaced with a double lumen line and I am now considering using eight dressings to protect the line when swimming.

I did once have a 'close encounter' of the type mentioned in the previous article. On one occasion I spotted something bobbing in the water nearby and soon realised that it was a poo floating in my direction! I exited the pool immediately and went straight to the changing rooms where I thoroughly cleaned my line and applied a fresh dressing, and everything was okay.

I really enjoy swimming and although this article did make me think, it has not put me off, but I will continue to ensure that I protect my line with plenty of Tegaderm dressings before entering the pool.

Enis Nichol



## NEXT ISSUE

Please send letters, articles and suggestions for future features to: Barbara Berry, 53 Leicester Street, Long Eaton, Nottingham, NG10 1FJ.

Email: [barbara.berry3@ntlworld.com](mailto:barbara.berry3@ntlworld.com)  
Telephone: 0115 849 1905

# Online

## CONTACT US

Justine Bayes 01933 316399  
Carolyn Wheatley 01202 481625

## HALF PINNT CONTACTS

Sharon Bell 0141 959 6701  
Sarah Green 01322 383507

## Editor:

Barbara Berry  
53 Leicester Street  
Long Eaton  
Nottingham  
NG10 1FJ  
Telephone: 0115 849 1905  
Email: [barbara.berry3@ntlworld.com](mailto:barbara.berry3@ntlworld.com)

## PINNT:

PO Box 3126  
Christchurch  
Dorset  
BH23 2XS  
Email: [PINNT@dial.pipex.com](mailto:PINNT@dial.pipex.com)  
Website: [www.pinnt.co.uk](http://www.pinnt.co.uk)



## PINNT PRIZE POT ENQUIRIES

If you would like to sign up to be included in the PPP – PINNT Prize Pot, then please contact Sarah on 01322 383507 to receive an application form.



## PINNT LEAFLETS

Advice on travel and insurance.

Advice on claiming disability allowance and claims and appeals.

Free to PINNT members.



## WEBSITE ADDRESS

Don't forget to log on to:  
**[www.pinnt.co.uk](http://www.pinnt.co.uk)**

where you can access all kinds of PINNT information, some of which is available to download.



EDITING: Due to space constraints, and in the interests of clarity, all articles and letters will be edited where necessary.

DISCLAIMER: 'PINNT has made every reasonable effort to ensure that the content of this newsletter is accurate, but accepts no responsibility for any errors or omissions. The views expressed are not necessarily those of PINNT and no reference to any product or service is intended as a recommendation.'

Designed and Printed by: 4FOUR2 Print Limited. Telephone: 01202 496444 (Christchurch) or 01747 824299 (Gillingham), Dorset.