PINNT
PATIENTS ON INTRAVENOUS AND NASO-GASTRIC NUTRITION THERAPY
Registered charity 327878

Price £2.00
Free to Members

Online

October 2006

Who Cares? We Do!

in association with:

Hospira
McKinley Medical
smiths

Friday lunch time in mid-June – the end of Carers' Week. Ester Rantzen speaks on the radio about her experience of caring for her daughter. Listening idly, my mind half on other things, something clicks and I begin to think.

How would it feel caring for somebody with a long-term medical condition plus parenteral or enteral nutrition?

Recently parents of very young children on PN have written about their 'fun and games' with babies and their PN – but how do you really feel, deep inside? Are you worried sick about whatever might happen next? How does the unfamiliar new routine of the PN regime affect your personal lives or your relationship with any other children or your extended family?

What if there is no extended family? How understanding are friends? Colleagues? How much can they be expected to understand and to make allowances for? What is happening to your career prospects, your way of life, the way you view yourself and interpret the world? How do you cope with emotions you might have never have experienced before?

How can anybody become the successful carer of a teenager? By nature teenagers rebel against constraints and constrictions and want to be one of their peer group. How do you motivate them to administer their feeds scrupulously nevertheless? How does it feel leaving a young adult to eventually take over responsibility for their own PN? How easy is it to take a back seat? To let go? What kinds of conflict arise when a teenager is on PN? How challenging is it to look after a teenager on artificial nutrition? What happens to the parents' or carer's own emotions? What kind of development does a carer have to undergo at this stage?

Parents naturally care and nurture their children and teach them to become independent and able to stand tall in the big wide world. However, being on artificial nutrition may extend the dependent parenting years.

How do you cope with an adult who has suddenly become dependent again through illness and artificial feeding?

continued inside. . .

IN THIS ISSUE

A lot of adult patients manage their parenteral and enteral nutrition quite independently. Or do we? If everything is running smoothly, certainly, yes. But, how often or for how long is this usually the case? Hand on heart, could we manage completely independently without our carers? Who keeps things going or picks up the pieces when we land in hospital yet again? Who makes sure we are alright and everything continues to run smoothly if we are out of sorts for a few days? How does it feel for you, our carers, to be forever there for us when we need you? How often have you had to put your life – or even your career – on hold to keep us going? How do you feel about all the ancillaries and pumps? Are you at ease with them? How do you cope if the patient is despondent, depressed, frustrated, upset – not only with his or her ill health but perhaps even more so with the hospital or a healthcare professional? How do you cope when we are grumpy, moody and – who knows – ever such a teeny bit unreasonable? How do you cope with the dilemma we cause when we ourselves sometimes do not even realise we are going through a difficult phase? Have you seen a change in your loved one? Have the effects of a long-term condition altered the person you first knew? Has he or she somehow become cynical, hardened or weakened by continual health problems and treatments?

Do you as a carer of somebody who is gradually getting on in years worry what might happen if you personally cannot provide all their care any longer, because you are not getting any younger either? Or, are you concerned about what might happen should your own health take a turn for the worse? Have you ever begun to wonder if a retirement home would cater for HPN?

Finally, when did you last have a holiday away from parenteral or enteral feeds? When were you able to be yourself, relax, and not be on call 24/7? Was it easy to switch off completely? And while we are on the subject: how do you feel about going on holiday with your charge? Can you, too, enjoy the break or do you find it turning into a strain just in case anything goes wrong and you are miles away from your usual medical support network? And: who takes your worries on board? Who listens to you and gives you support?

Would it be a good idea if you, as our carers, put pen to paper from time to time to let us know how you feel? Certainly, you are hard pushed already, many carers valiantly perform their role out of love and devotion without even realising the extent of their role. But might it not be beneficial for all the PINNT community if you gave us the opportunity to listen to your concerns and experiences? Or, maybe you want to share lighter moments like, for example, when, in the middle of the night, I was suddenly woken by the screaming alarm of my malfunctioning pump to see my husband and carer jump up like a flash of lightning to try and stop the smoke alarm.

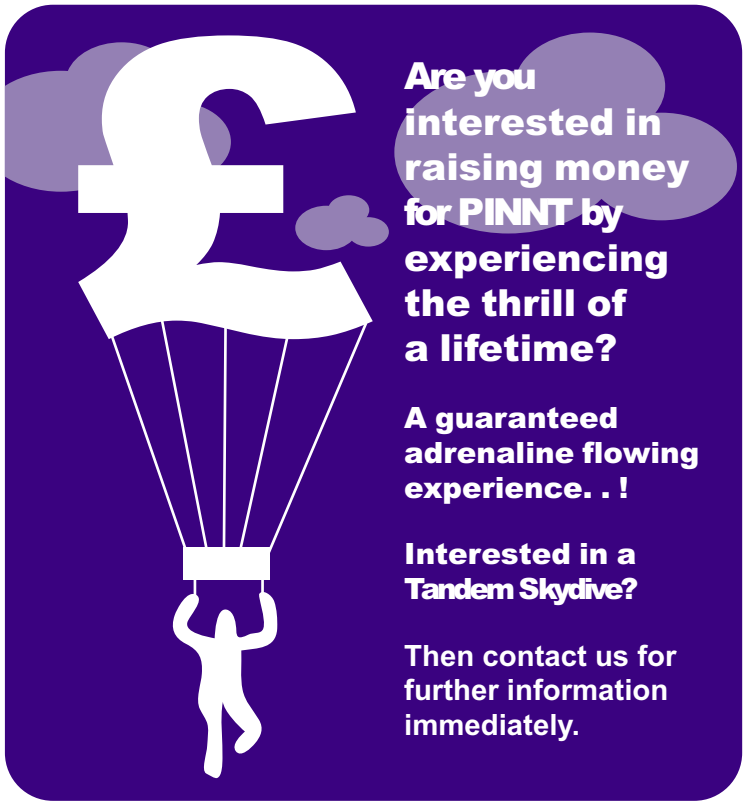
Carola McRae

FROM THE EDITOR

I need your help! So that we can continue printing the features that you want to read, we have enclosed a readership survey with this edition of Online. Please take a few minutes to complete it and let us know which features you enjoyed the most (and the least) and we can include more of the features you like and less of the ones you don't! Please add as many extra comments onto the survey as you like using additional sheets of paper, and return it to me at the address given in the 'Contact Us' section.

Barbara

Online Editor



PINNT PRIZ£ POT ENQUIRIES

The winners of the PINNT Prize Pot are:

April 2006

1st	82	Mrs Jeffery Kuyper	£113
2nd	172	Christine Mogford	£68
3rd	27	Geoff Simmonett	£45

July 2006

1st	137	Diana Burgess	£113
2nd	75	Vanessa Lloyd	£68
3rd	59	Master Lucas Moran	£45

GRADUATING FROM THE UNIVERSITY OF LIFE

"I'm looking forward to getting my life back," many people say as they begin artificial nutrition. November 2001 was the start of my journey on PN. I had just been diagnosed with visceral myopathy and at the time malnutrition, pain and sickness, were so severe intravenous nutrition was the only option offering me hope for a future

Long term illness had been a feature of my life for years, but except for the last few months before hospitalisation, when my symptoms were so severe, I had managed to live a full life achieving the aims and ambitions of any other "normal" girl. I think sixteen is a difficult time for anyone, with unique issues; for me it didn't take long to feel that PN had taken my life away. There seemed few comparisons to my "old" life and in some ways this got worse.

Previously I had fully participated in all aspects of school life, achieving high standards both in the academic and extra activities I embarked upon. I had a wide range of hobbies and led an active social life, with activities such as dancing, playing the flute, drama etc. With a large friendship circle, we went shopping, to the cinema, on girlie nights out and to theme parks, and enjoyed regular family holidays – Greece being a favourite destination.

At school, I won a number of academic and other prizes, leaving with 10 GCSEs: 8A*s and 2As. I had a job, and was looking forward to learning to drive, saving for a car, completing my A levels and going to university.

When I first came home on PN, I couldn't go back to sixth form (I had missed too much that year and was still infusing for 18 hours a day). It was hard knowing my friends were getting on with their lives, but by the next year I had reduced my PN hours and so was able to complete my first year at sixth form, achieving 4 AS levels at A grade, (just, it did almost kill me – literally! The day after my last exam I was in hospital!)

Spending the entire summer in hospital was not good for my health, or morale. Somehow I attended interviews, the next term at Oxford University and was offered a place to read physiological sciences at my college of preference. However, I wasn't able to take up that or any other offers as I spent most of the next year in hospital.

It shocked me how ill you can feel, and how things can always get worse! It wasn't until about a year ago that I started to make improvements of any considerable measure. I have become more realistic, accepting I have limitations, but being grateful and making the most of the things I have when I have them, as sadly setbacks and crises are possible at any time. I've recently started an Open University course, something I could only have dreamt of not too long ago. This has provided me with a realistic way to study at the moment, with more flexibility, from home and with the support of a personal tutor.

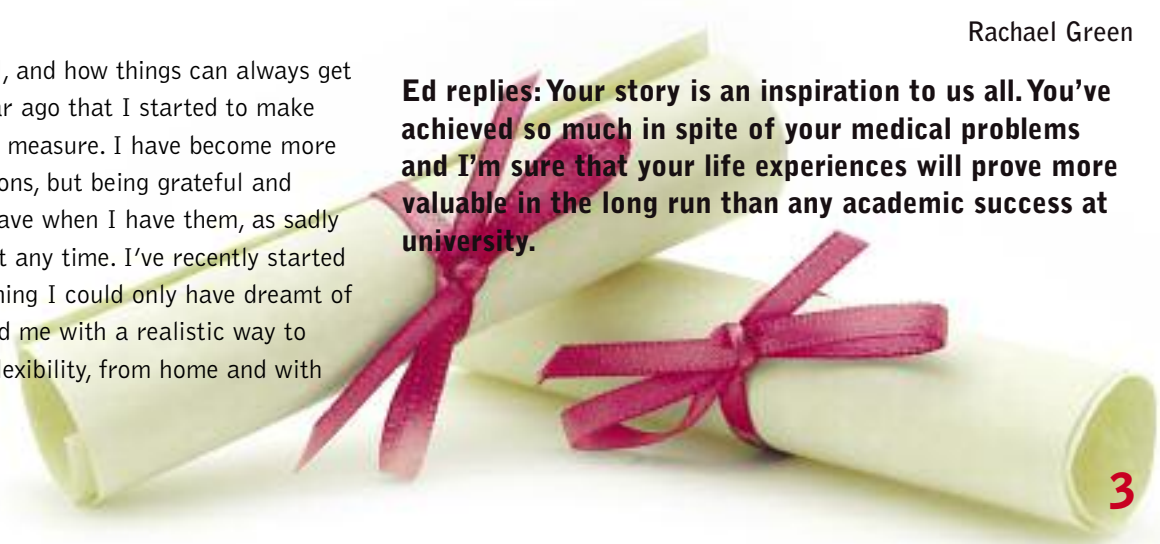
I'm grateful to be under St Marks now as they have more experience with unusual conditions and management of PN; they have also been very good about listening to my views and have done as much as possible to keep me at home. I'm still learning the differences in child and adult care; they have very different mindsets and priorities!

Life is a journey for us all, and I don't think we ever stop learning. The experiences we have make us who we are. I may not have learnt as much academically as a number of my friends, but I have learnt a vast amount of other things which they may never have the chance to.

This summer, many of my friends graduate – something I'm sure will still be hard – but I've come to accept that no one can predict what will happen in the future, so making the most of what we have when we have it and being optimistic is the most constructive way we can all live.

Rachael Green

Ed replies: Your story is an inspiration to us all. You've achieved so much in spite of your medical problems and I'm sure that your life experiences will prove more valuable in the long run than any academic success at university.



FROM THE CHAIR

Phew, what a summer! Hope the heat did not affect you too severely. We know many of you struggled on occasions to keep on top of your fluid requirements.

Our editor has asked that my report be kept to a minimum to ensure as many of *your* contributions as possible are printed. I would, however, like to thank everyone who returned the survey about HPN and line infections – it was a great joy to receive so many. We promise to provide feedback via Online once the data has been analysed.

Short and sweet – take care.

Carolyn

Chair PINNT

A Recipe for Life

The Domestic Goddess's Guide To What's In Your Parenteral Nutrition

Meal planning can be quite an art, the same applies to parenteral nutrition planning. Only the finest ingredients, measured perfectly, will do. Ironically I'm not much of a cook but I can rustle up a balanced PN prescription in a few minutes.

Just like making the perfect mayonnaise, producing a bag of parenteral nutrition that contains fat takes skill to balance the ingredients so that the beautiful creamy emulsion does not crack. Endless hours slaving over a hot pan – well, actually a stability table – can produce perfect results every time.

Ingredients:

A parenteral nutrition solution can contain up to sixty individual ingredients. The addition of fat transforms the mixture into an emulsion. Home parenteral nutrition regimens are as individual as the patients they are made for.

Instructions:

The following process should be carried out in a very, very clean environment, certainly not on your kitchen worktop.

1 Select an appropriate container

Once the ingredients are all assembled they should be carefully measured and transferred into a suitable bag, preferably one that will not allow oxygen in – this protects the vitamins in the bag.

2 Take a suitable quantity of calories to maintain energy levels

The calories in the mixture are provided as glucose and fat. Glucose is the preferred source of carbohydrate calories. Fat is provided as triglycerides: these are a combination of mono and poly unsaturated fats. These are formulated into an emulsion so that they are stable and do not separate.

3 Add enough amino acids to support protein production

Protein is provided as its building blocks, amino acids. There are eight amino acids which are considered 'essential': these are provided in all solutions that are used. All the other amino acids can be made by the body.

4 Add a pinch of salt (or two)

The minerals in the regimen – sodium, potassium, calcium, phosphate, magnesium and chloride – are all added individually. The type of product used is carefully selected to optimise the stability of the bag as well as to meet the patient's requirements: for example, using an organic phosphate salt rather than an inorganic salt (sodium glycerophosphate rather than disodium phosphate) to reduce the risk of precipitation, or using sodium acetate rather than sodium chloride to help reduce chloride load for patients with kidney dysfunction.

5 Garnish

Vitamins and minerals are usually added as combination products which contain the currently recommended daily intake of all the vitamins and trace elements.

Eating is an important psychological and social function. Although we may not be able to tickle your taste buds or tempt your senses, we provide a balanced diet with as much care and attention as the most prestigious chefs and we won't force you to eat your five portions of fruit and veg.

The average parenteral nutrition bag will cost more than a slap up meal at a posh restaurant, but remember – you're worth it.

Rebecca White
Lead Pharmacist: Nutrition & Surgery, John Radcliffe Hospital, Oxford, and Chairman, British Pharmaceutical Nutrition Group

Eating is an important psychological and social function.

MS, My PEG and Me

I was diagnosed with Multiple Sclerosis when I was twenty five, a couple of weeks after I had become engaged. Steve and I celebrated our silver wedding anniversary last year, so this diagnosis didn't send him running for the hills!

As is the way with MS (a condition which I don't think can ever be described as typical – every individual is on their own unique path) it has had its ups and downs, starting out in the relapse/remission pattern and turning into a secondary progressive form as time went on. About ten years ago I began experiencing extreme difficulties swallowing, with a gradual loss of a gag reflex. Food became a real torment and I was rapidly losing weight, not that I had much to lose in the first place. This led to me having my PEG about nine years ago and, although it has been somewhat of a mixed blessing, it has facilitated my continued existence, so I am very grateful for that as life is good.

However, I am saddened at the very negative opinions expressed, in ignorance, in the media and the like, about artificial feeding in long term conditions, be they degenerative or not, even to the extent that death would be preferable. My PEG *is* a big deal, but no more so than the day when a wheelchair became a necessity.

How I wish that I had learned of PINNT then as I wouldn't have felt so isolated. I had a lot of problems settling to the feeds, which were somewhat rich for my innards, and for which I got very poor professional support. Many of my difficulties are related to my MS: lack of dexterity and severe muscle spasms, such that they often break the balloon holding the PEG in place. I was a bit of an old hand with my PEG when I first heard of PINNT, but it has proved invaluable to me. Something should be done to persuade doctors, dieticians, specialist nurses and medical professionals in general to put people in touch with PINNT as a matter of course.

How I wish that I had learned of PINNT then as I wouldn't have felt so isolated

At present I am on a Jevity feed as it is the one that is most suitable to my needs as well as being totally vegetarian and kosher. I take nothing by mouth so my medications have to be in liquid form. I also have a supra-pubic catheter so I have to ensure that I also take enough water too.

When I first had my PEG I tried to feed during the night, as seemed to be the norm, but this was an abject failure. Steve found that he couldn't sleep with the pump going and he did not appreciate having to get up during the night to flush through, change bottles, etc., especially as he has a heavy and tiring job. More than once the tubing managed to become disconnected, which I wouldn't realise until I found myself lying in a cold, sticky puddle of feed. I switched to daytime feeding, which seems far more natural to me. Steve sets me up before he heads off to work at 6.30 am, and I have a carer calling twice during the day. I have a Flocare Micromax 200i pump which happily moves around the house with me and my wheelchair. The district nurses quite happily change the PEG tube as and when required, either because it has reached its change date or because I have broken the balloon with muscle spasms. I have a Corflo gastrostomy tube with 20Fr balloon, although I only have 15 mls of water in it as this smaller amount, whilst making no difference to the security of the device, makes it less likely that my stomach muscle spasms will break the balloon. I know there are less obtrusive, whizzier tubes, but they require hands that function better than mine.

Another part of my MS has been severe sickness: at first on an irregular basis, but gradually becoming a continual thing. As others will realise, vomiting, dysphagia and poor cough reflex are not conducive to one's health or peace of mind. The neurologist said that this is uncommon but not unknown. It is controlled by a constant subcutaneous infusion of cyclizine and dextramethasone via syringe driver. The nurse comes in twice a week and relocates the site of the needle and Steve makes up the syringes for the other days: he's happy so long as he doesn't have to have anything to do with the needle end!

We have no children but we are very fortunate to live near my sister and brother, each of whom have three children who we see a lot. My brother's youngest is ten, and the fact that I don't eat when we are with them for a meal has never been a problem for any of the children: they accept it as part of life. My mother, on the other hand, never did cope with it, and my in-laws find it difficult, all sitting down to a meal and me not eating with them. Normally, when it is just me and Steve, he eats alone while I do something else. We did sit together while he ate, but he felt as if he was on show, so we adapted our routine to overcome the unease he felt.

I don't work – I haven't done for many years – but I read and study and I write book reviews, although this has become a bit curtailed as I get less able. Sometimes a deadline is a good incentive, but it just becomes a worry if I'm not well enough to meet it.

On my kitchen wall I have a cartoon. A giraffe and a hippo are having a conversation.

> The giraffe says, "How's life, Rory?"
>
> The hippo replies, "Fantastic."
>
> The giraffe says, "Really?"
>
> Rory the hippo replies, "Yes – but it's not something I'd recommend to everybody!"

Melanie Holdsworth

How To Get Back to Work in Ten Easy Steps

Of course I wish it was that simple – just ten things to say or do that could guarantee full-time meaningful employment. Well, we all know that life isn't that simple. If it was we probably wouldn't be in the position we are in, coping with illness and artificial nutrition.

However whilst there aren't ten easy steps to employment, in my experience you could say that you only need one thing to get you back, or in to, work – shear good old fashioned determination. If you have this, I can't tell you what job you'll get, how much you'll earn or how far up the career ladder you'll go, but you will get there. It's probably more accurate to say that one thing is for certain – you won't get anywhere without it.

I remember being in hospital for a seven month period from the beginning of 1995. Life couldn't have got much worse: seriously ill and underweight, unable to walk very far, wedding cancelled, lost my job etc. I was in a teaching hospital and I was glad of the constant interruptions from doctors and their students, learning from the unusual case in bed four. If I'd had a £1 for every history I'd had taken by a student, I could have retired there and then, never needing to work again. They would roll off the usual questions of how old are you, and so on and so on, but one question that was always guaranteed to annoy me was "What did you used to do for a living?" Used to! Past tense! "I am a sales and marketing assistant," – *present* tense. Unfortunately I lost my job, due to my illness, eighteen months in.

Throughout my treatment there seemed to be an unspoken assumption that I wouldn't work again, that life on PN would be enough to cope with and of course that was if things worked out and I made it home in the first place. I could see the look on the doctors' faces when I said I wanted to get back to work. "Yeah, right," but with a half smile so as not to upset me. Now, twelve years later, I get a perverse sense of satisfaction knowing that I probably earn as much as they do.

I also remember my very first time back in clinic after finding a job. I was dressed in a full suit and tie – on purpose of course. My consultant used to appear from his room, call a name, and then disappear back into his room, whilst you made the long trek from one end of the corridor to the other. This time was different though. He caught a glimpse of me as I stood up, did a double take and then just stood there, beaming with a smile, proud of his prodigal "patient" son. From that day on, his very first question on every visit was always "How's work going?" Of course I repeated the scenario on the ward as well!

The reality of being out of work and finding a new job is, of course, much harder. There were five years in between the start of my illness and the day I walked back down that corridor.

In terms of practical help in finding a job there are no secrets, no guarantees. You just have to have that determination, a lot of persistence and then do all the usual things: job adverts, search the internet, visit job centres and agencies, listen out for word of mouth, and of course you still need to be the best candidate for the job.

What you must do right at the very start, though, is to be honest with yourself and be realistic about what you can manage to do: what time constraints does your artificial nutrition impose on you and what does your condition allow you to do. It is no good saying "I want to be an airline pilot," because you're simply not going to be able or allowed to do it. I was lucky in some ways in that my underlying condition had been treated and for all intents and purposes was a thing of the past. I simply had to cope with a stoma and HPN. However, if your underlying condition, as well as your artificial nutrition, is going to restrict what you can and can't do, you have to take this into account.

Of course if you had a job beforehand, the easiest place to start is with your employer if your position is still being held open for you – but again be realistic about what you can manage. You may be offered a different position, different responsibilities, reduced hours and even reduced pay. It may be a hard pill to swallow but seriously think about accepting it, just to get back to work, and then, when it's right, move on.

To be honest the only thing you need to try and achieve when returning to work or starting work for the first time, is to change that last "Professional Patient" entry on your CV. Even if it's not quite what you want, take a job just so you can get that last entry changed. Then when you're sitting in front of an interviewer for the job you really want, you don't have to say "I've been ill," when they say "Tell me out the current position". This could always be voluntary work – at least it will show you and a potential employer that you're willing and able to work, that you are reliable, trustworthy and not content to accept life on benefits.

There are a number of organisations that can help arrange some short term, voluntary work experience for "disabled people". I was referred to an organisation called the Shaw Trust by my local job centre. I found them very helpful despite their stereotypical idea of what a "disabled person" was. They found me two months' work experience with a company in the same industry that I had worked in before and it was great. I had a reason to get out of bed again, a purpose in life and responsibilities to undertake. Of course they used me as two months' free labour for all the horrible boring jobs nobody else wanted to do, but I did it with pride and determination to do the best job I could. I left with only a "Good Luck in the Future" card from them but also I had that revised last entry on my CV.

I can't offer you too much advice on what to do and say at job interviews – everybody is different, everybody's condition is different and every interview and interviewer is different. That's the same for every interviewee, previous illness or not. The only thing I would say is be honest if asked a direct question about your health. Outright lies can only come back to haunt you. However (and perhaps I shouldn't say this) but you can be economical with the truth. I said before that I didn't work for five years due to my illness, but my CV says it was three and half years. My employer left it for eighteen months before writing to me to say my job could not be kept open for me any longer, so that's when I officially became out of work as far as my CV is concerned!

As I said before, you have to be realistic. If you need PN for fifteen hours a day or you need bolus feeds via your PEG throughout your working day, you have no choice but to be completely up front about it. So be up front about it! Be proactive and talk positively about it. Don't leave it till the end and say "Oh, by the way I need to tell you about. . ." Believe me (from personal experience) this approach only goes to amplify the perceived problem ten fold. If you present it as a problem or an obstacle, the interviewer has no choice but to assume it is going to be a problem and you probably won't get the job. Job interviews for anybody are all about confidence and you have to exude confidence about your artificial nutrition and your ability to cope with the job despite everything else as well.

However, as I said, you can also be economical with the truth. If you're not asked about a certain aspect of your condition and it's not critical to tell them, don't. In the interview for my current position I was asked why there was a three and half year gap in my employment history, so I told them I'd been ill. When asked why, I told them I'd had some problems relating to my bowel. When asked if all my bowel problems were sorted out now, I said yes. I had been totally honest with them, but they then changed the topic of their questions. Therefore I didn't elaborate and tell them about my PN. Now I only feed for ten hours a day, so I can get away without having to carry my PN around during the day.

Just as a final thought about been realistic: I found to my cost that those interviewers who said "Oh no, that's not a problem," and changed the topic of their questions when told about my condition, were the ones for whom it *was* a problem. They just wanted to get the interview over with quickly and move on to the next more suitable applicant. Some weren't that tactful about it either. We all know it is, or at least has the potential, to be a problem and we have to be realistic about that. You just have to move on and tell yourself you wouldn't want to work for them anyway.

I went for an interview once where I had to endure a fifteen minute grilling about all the ins and outs of my condition. I was even asked if they would need to provide a ramp at the front door (I assume for my non-existent wheelchair). This was despite having walked into the interview and having been taken on a (walking) guided tour around his factory. I left deflated, but within an hour of leaving, he'd rung and offered me my first job since recovering from illness. I was elated.

I remember returning to work after my first period of time in hospital after starting the job. I was very nervous, made all the worse when the first thing my boss said was "We need to have a chat later." After the most nervous hour of my life, fully expecting the sack, we had our little chat. He asked if I was feeling better, told me how much they'd missed me and then told me that he hadn't realised just how much work I'd taken over. Then to my amazement he gave me a two thousand pound pay rise! My first line infection was very cost effective. Mind you, it hasn't worked like that since, but as I said you have to be realistic!

I've had two further job changes since then, each one a step up the career ladder. You can't plan for being ill, or needing to go into hospital, and therefore you shouldn't try. You definitely shouldn't let it hold you back in terms of your career. Deal with the consequences of being ill when they happen and then carry on. The reality of the situation is that you're not going to get promoted if you're ill and off work more than at work. Right or wrong, that's just the real world. Therefore, to hold yourself back artificially, although I'm not sure that's the most appropriate word in our case, is just self-perpetuating. Have that determination to go out there, work to the best of your ability and tell yourself that you deserve that pay rise or promotion.

Most importantly never, ever, let being on artificial nutrition get the better of you.

Ian Swain

FOCUS ON...

Some of our volunteers have been working for PINNT for so long that it occurred to us that our newer members wouldn't know much about this dedicated group, or their history with PINNT – so we aim to remedy this. In this edition we are focusing on Jackie Huff, our regional co-ordinator for East Anglia, and Geoff Simmonett, PINNT's new treasurer. We begin by handing over to Jackie:

Jackie Huff

Hello to you all. I have been a member of PINNT for thirteen years and I have been helping to organise our regional meetings in East Anglia for about eleven years. I also joined the Executive Committee at that time and I have to say that it has been worth every minute. Arranging meetings can be a little stressful at times, but it is very rewarding to hear that people have had a good time and have enjoyed chatting with and getting support from others in a similar position to themselves.

I have been on HPN for thirteen years following a rather traumatic series of hospital procedures that didn't go as planned and resulted in surgery to have my stomach and the first part of my small bowel removed. I was fine for about a year after the surgery but then the muscular movement of my gut decided to go into reverse and I ended up on HPN for six nights a week.

I feel that I cope very well with this treatment, but it has taken time. In the beginning I was very frightened and helped myself through this by making sure that whenever I was connecting or disconnecting I took my time and concentrated on the procedure, no matter what was happening around me. I still follow this rule, but I am not frightened any more. The best piece

of advice I could pass on to others is to give it a chance – everything is strange to start with, but if you are patient and give yourself credit where it's due, then everything will turn out okay. Be sure to talk out your concerns with others and don't keep anything hidden even if it seems silly to you. Nothing is silly if it is bothering you and it won't seem silly to those who support you.

I think that the hardest thing for me to come to terms with is the fact that I am unable to eat normally. I find that other people are reluctant to dine out with someone who can't eat and drink in the same way they can. However, my medical problems have had some positive effects on my life. I have made some great friends through PINNT, friends who really understand what I am going through. I am also committed to dedicating my time to helping other people come to terms with life on artificial nutrition and I feel that working for our charity has given me a personal worth.

So, what has HPN enabled me to achieve? Well, it's 2006 and I'm here writing this article! I have a great quality of life and I now have the privilege of seeing my grandchildren grow up. I am able to travel and take holidays abroad and experience cultures in different countries. And what does the future hold for me? I'm going to continue to enjoy my grandchildren, help others where possible, keep on with the volunteer work, potter around the garden in the summer, train my new puppy Pebbles and help and support my husband during our 'old age' as he has done such a good job looking after me for all these years.

Jackie Huff

Geoff Simmonett

With a little arm twisting from your editor, here is the story of how I came to have a PEG and become involved with PINNT:

In August 1982 my doctor prescribed antibiotics for catarrh and slight deafness in my left ear. After a second dose of antibiotics brought little change, I was sent to an ENT specialist and subsequent tests showed fluid build up in my inner ear, which could be drained by fitting a grommet into the eardrum. The grommet was fitted on Monday, 7th September and at the same time the consultant examined my adenoids and took a biopsy. As promised the consultant rang me at home on the Friday and invited me to come in to see him to discuss his findings. I asked if it was my adenoids and he said no, but he'd still like to see me. I asked him why he couldn't tell me over the phone, and was it more serious than he'd expected. He insisted that he would prefer to discuss it in person in his office. Alarm bells rang. "Are you saying that you have found cancer?" I said. Silence. Then the doctor's voice, "Were you expecting something like that?". "To be honest I wasn't," I said, "but as you were so insistent about visiting your office it had to be more than we expected."

He then confirmed that he had taken a biopsy from a tumour that was growing in the nasal pharynx above my palate at the back of my nose. He said he thought it was treatable and that he would refer me to a colleague. Concerned that he had broken the news over the phone, he called me back a couple of hours later to see how I was. I said I was fine and I hadn't put my head in the gas oven, and anyway we were all electric! He said he'd contact me on Monday after speaking to his colleague.

The following week his colleague told me that radiotherapy would be a more suitable option than surgery and that the treatment, which consisted of twenty four doses spread over eight weeks, with a weekly top up injection of chemotherapy, would make me very ill. When he told me that there was a better than 50/50 chance of success as they had caught the cancer early and it was only the size of the top half of my thumb, I agreed to go for it. When the treatment started the following week I weighed in at 13H stone – at the end of my treatment eight weeks later I was down to 10 stone. The back of my nose and throat were severely burned by the radiotherapy and I could not eat solid food. I had a diet of Weetabix in hot milk, soup and rice pudding. This was when I was first introduced to artificial nutrition to supplement my diet. It was called Clinifeed and was developed for astronauts – and I didn't even have to go into space to get it!

The treatment did make me ill as I had been warned, but the final outcome was successful and three months later I was able to eat solid food and after six months I was back at work. The tumour had turned to ash and I had regular check ups for any recurrence for five years, after which I didn't have to return. There were a few side effects: the radiotherapy had burned out the saliva glands in my cheeks and throat and left me with a dry mouth; it also caused my gums to shrink as my mouth was too dry and my teeth suffered. But as they say, it's a small price to pay for still being alive and able to lead a normal life.

By now you're wondering why I have a PEG! Well, after twelve years of leading a very full life, I found myself back in hospital with pneumonia twice in six months, and tests showed I had TB, which was successfully treated. However, on New Year's Day 1996 I was back in hospital with pneumonia again and was unable to swallow anything without choking. I was put on naso-gastric feeding and this time neurological tests established that my problems had been caused by the radiotherapy I'd had fourteen years before. It seems that radiotherapy can continue working for up to twenty years after the treatment has finished, and this had slowly been destroying the nerves and muscles in my throat and mouth, so that when I swallowed food and liquid,

rather than going straight into my stomach it was pooling in my throat and spilling into my lungs, thereby causing the infections and pneumonia. My jaw was also tightening up and I could no longer open it wider than a quarter of an inch, and my epiglottis no longer closed over my windpipe to prevent food and fluid entering my chest.

The answer was to have a gastrostomy, which has taken my weight from 10 stone to a comfortable 11H stone. Fortunately my local hospital has a good gastroenterology department and I have received excellent support from my specialist and the community dieticians who have always been on hand. Three years ago my jaw finally seized up and I had an operation to open it wider as the hospital were concerned that if I needed to vomit I would not be able to expel it and I would probably choke. Due to the radiotherapy the jaw muscles had become hard with no elasticity. I had the operation but the result was not entirely successful as it has given me some movement but affected my speech. I had been working part time until then but it is difficult for people to understand me on the phone, and even friends and family have difficulty in a one-to-one situation. I also have to be careful with my chest as I'm vulnerable to infections as the pneumonia has left me with bronchiectasis in the base of my lungs.

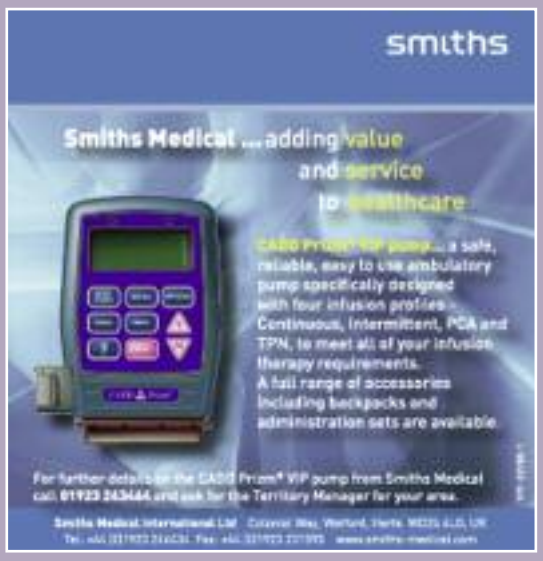
The important thing to remember is that life goes on. If I hadn't had the treatment twenty four years ago, I wouldn't be writing this now for Online. There have been a lot of ups and downs but wherever I go I see someone who is worse off than myself and I make the most of my life. I still take my wife out to dinner at least once a week. I did get some funny looks to start with but the restaurants we go to all know me now and think nothing of it – and we have never been refused a table, even when they are busy. We still get invited out to our friends' for dinner or a barbecue and if I'm due for a feed I just slip into the other room and shoot up. I have also completed a course in computer skills and internet design, which I hope to develop.

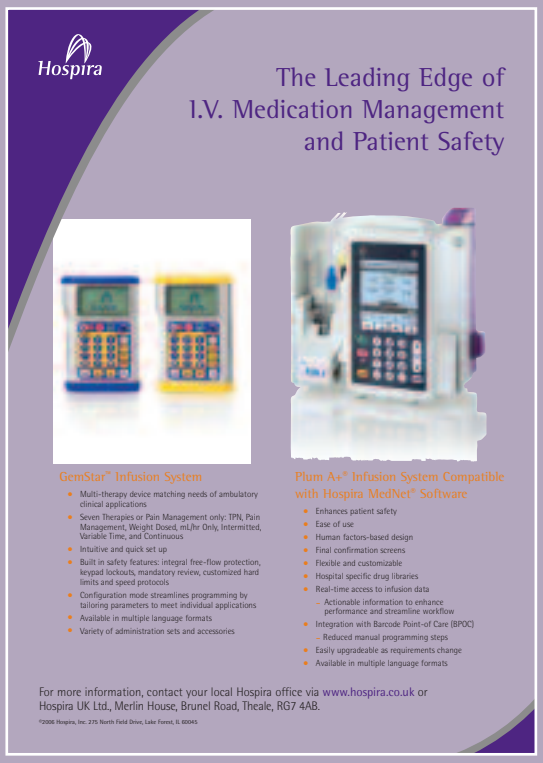
I realise that being on artificial nutrition has its difficulties, but we can't let it rule our lives. In the last eight years I've been to the Caribbean cruising, Florida, Cyprus, Israel and Spain as well as Weymouth and Scotland. I even have the odd gin and tonic – a little sip for taste and I use my syringe to put some through my tube, so I join in and get a little merry (but obviously I wouldn't do it if I were on medication!)

My philosophy has always been to make the most of life no matter what – it's not always easy, but it's a lot more fun than sitting back and feeling sorry for myself.

Geoff Simmonett

SPONSORS' FEATURE





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

Half PINNT

TEACHING LUCAS

As the end of Lucas's Reception year in school rapidly approaches we have been asked to comment on how things have gone – highs and lows, difficulties and challenges. I think I can speak for all the members of the Reception team when I say that the Highs have it!

Before Lucas began school, all relevant staff had a thorough briefing as to his needs, emergency care and procedures, and although we were initially apprehensive and unsure of our ability to cope, the details of care needed were explained in such a way as to lessen our concerns. Close contact with his parents during the year has ensured that his medical and academic needs have been balanced appropriately.

We are fortunate to work in an 'inclusive' mainstream environment where any of the children's needs or differences are accepted as part of everyday school life. Our 'inclusive' provision allows us to have a greater staff/pupil ratio than is the norm in many schools and this, combined with the support hours specifically provided for Lucas, has given us time in the day to monitor and meet his needs, particularly on the days after no PN.

The entire Reception staff team have felt privileged to have Lucas in class, his engaging personality and great enjoyment of life have been an inspiration to us all. We love his sense of humour, his eagerness to learn and experience new activities, and we are proud to have been a part of his physical and mental growth and development.

In order to facilitate a seam-free transition into Year 1 we are arranging a briefing session between his parents and the Year 1 staff, where all will be able to share concerns and learn how to support, monitor and meet his specific needs, in class, at play, and at meal times.

We will miss him enormously when he moves on into Year 1, but console ourselves with the thought that he is only a classroom or two away, and that we will be able to have lively conversations (and the occasional cuddle) with him in the playground.

He has been a truly valued and valuable member of the class.

Class Teacher – Jean Ingram,
Classroom Support assistants – Lynn Tribe,
Julie Talmage Julia Woodward

Ed Replies: Thanks so much for following up our article 'Starting School on TPN' in the June edition of Online, by telling Lucas's story from the teachers' point of view.

Left to right: Julie, Jean, Lucas, Julia and Lynn

Intestinal Transplantation – Your Questions Answered

We have received several interesting questions from readers following Dr Woodward's article on intestinal transplantation in the June edition of Online. Here is his response to one of them:

Are there patients with certain conditions that will have a better success rate for intestinal transplantation?

I have heard a number of radio interviews where politicians from opposing camps use the same set of figures to justify their own (opposite) viewpoints – we should always be wary of statistics! When we consider the overall outcomes of intestinal transplantation, there are a lot of different aspects that have been 'lumped together'. For instance, the operations themselves may be very different. The mix of patients is very wide, including children and adults; some are very well and at home before the operation, others may be extremely unwell and in hospital. The figures include patients with a broad range of different underlying illnesses that have resulted in intestinal failure that requires parenteral nutrition. There are also many different reasons why the parenteral nutrition may not be working well. As far as intestinal transplantation is concerned, every patient is an individual, and the risks and likelihood of a good outcome will vary from person to person. Whilst we can use the outcome figures to tell us roughly how good this operation is overall, we should be very careful in using this data to predict an individual patient's chances of doing well after the operation. For some it may be substantially better, and perhaps for others not as good as the overall figures would suggest. If we break down the results into different categories – for instance the underlying illness – then there are fewer patients and therefore less information from which we can draw any meaningful conclusions. Finally, overall results of intestinal transplantation continue to improve year by year and this makes it difficult to compare the outcomes across different groups of patients over different years.

Dr Jeremy Woodward, Consultant Gastroenterologist
Addenbrooke's Hospital, Cambridge

For this year's AGM we bravely booked dedicated meeting facilities. What a difference this made, the venue was fantastic and had everything to make our meeting a huge success. The turnout was excellent, more than 90 people came to support their charity. Everyone made the most of the opportunity to chat and mingle. After the serious business of the AGM itself, the theme turned to fun and everyone joined in with the workshops and fundraising events, culminating in the presentation of £1348.00 by Enis Nichol which was raised by organising a sponsored walk over the Forth Road Bridge.

Dr Jeremy Woodward was our Keynote Speaker and gave a fascinating talk about the evolution of intestinal transplantation which we are pleased to be able to print overleaf. Barbara Berry and Teresa Culverwell then spoke about their personal experiences of artificial nutrition (excerpts follow). Full transcripts of Barbara's and Teresa's talks are available on request.

The workshops were just amazing: McKinley, Hospira and Smiths Medical bravely agreed to each host a workshop to demonstrate their portable feeding PN pump. This was a golden opportunity for people to ask questions and find out exactly what each of these pumps could do. It was clearly stated that PINNT was not endorsing any of them but firmly believed that patients and carers should be aware of what was out there. The feedback was excellent, each of the company representatives said direct contact with users gave them a better insight into the people they support. Each company welcomed the questioning and promised to keep PINNT in the loop with updates and feedback.

Our meeting was supported by —

Calea
Clinovia
Hospira
McKinley
Nutricia
Smiths Medical

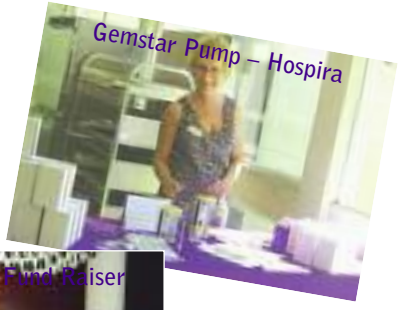
Thank you
for your attendance
and continued support

Rachel, Enis, Emma and Carolyn

The Holiday and Travel workshop was also a great success – insurance was top of the list and everyone contributed in giving advice and sharing experiences – supporting other people to plan effectively for holidays. Going abroad should not be seen as the only type of holiday – wherever you go planning is the key factor.

The fund raising was fun, the speakers were amazing, the children played games in the beautiful gardens and the afternoon came to a timely end once everyone had soaked up the support they'd received that day.

A successful meeting, excellent attendance and to sum it up 'PINNT doing what it does best – supporting patients'.



The Old and the New – Cambridge and Intestinal Transplantation

New Hall College in Cambridge – the location of this Annual General Meeting – is a group of modern buildings set in one of the best preserved mediaeval cities in the country. The juxtaposition of the New and the Old is the theme of this talk, and gives me licence to describe some of the history of this beautiful town (in the hope that you may have some spare time to look around it after the meeting) and its link with a more recent development – intestinal transplantation. Cambridge is rich in myth and legend, based rather loosely on fact – and so often (thanks to modern media) it is the same for innovations in medicine. Whilst I may regale you with some tales of old Cambridge, I hope also to debunk some modern myths about intestinal transplantation. . .

Although Cambridge is famous for its University, the town itself dates much further back. The remains of the Roman establishment lie beneath our chairs here on the edge of the mediaeval city. Possibly more surprising than the fact that there is a hill in Cambridge (we are actually on the top of it here!), is that it was once dominated by a Norman castle, of which only an earthwork remains. Astonishingly for a town so far inland, Cambridge was once an influential port, being the furthest point that could be reached by barges from the coast along the rivers Ouse and Cam. The University is the *second* oldest in the country. Legend has it that in 1209, a group of disaffected monks were thrown out of Oxford for drunken and disorderly behaviour and decided to set up in opposition in a rather inaccessible and out of the way place. Perhaps the traditional rivalry between the two universities dates back all this time – or maybe this is merely the explanation for the large number of taverns in the city!

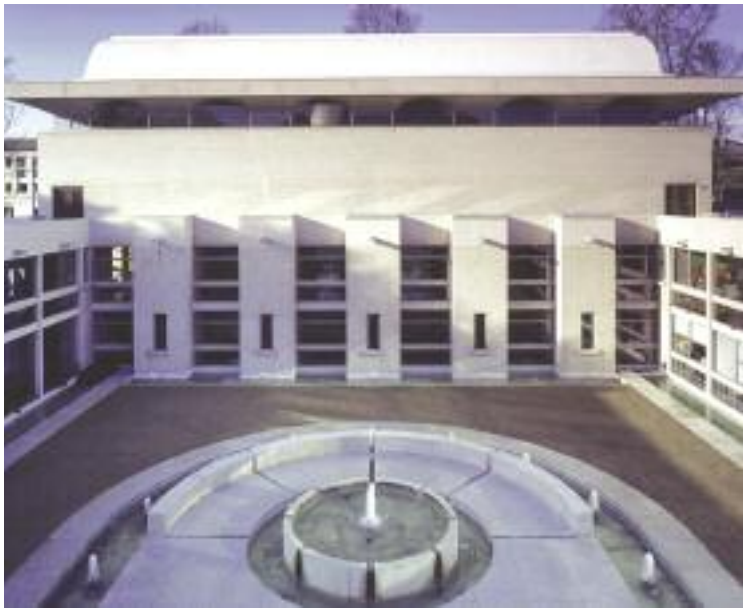
Indeed it is with one such establishment – and not a college – that one of the major advances in modern medicine is accredited. Legend (and a blue plaque on the wall) tells us that it was at the Eagle pub, an ancient and well preserved coach inn in Bene't Street, that James Watson and Francis Crick came up with the idea of the double helix as the structure for DNA. With this discovery, the chemical code in which our genes are written was cracked, and biological science entered a new era.

The association of Cambridge with genetics continued and it was here through the work of the Sanger centre and others that the entire human genetic code was unravelled only 50 years later. . .

In the same year as Cambridge scientists pondered the meaning of life over a beer, the first organ transplant operations were carried out in humans. Kidneys were the first organs to be transplanted but by the end of the 1950's, the surgical techniques for many organ transplant operations – including intestine – had been described.

In 1965, the year that New Hall college was built (on land owned by descendents of Charles Darwin), the first human intestinal transplant operation was reported in the United States. The situation was desperate, as at this time parenteral nutrition had not been developed and unlike today, there was little hope for patients with intestinal failure. Unfortunately, early attempts by these brave patients and their surgeons were not very successful, and the transplanted intestine was 'rejected' rapidly by the patients' own immune systems.

Rejection of transplanted organs occurs because the body's defences rely on a 'friend versus foe' recognition system. Put very simply, every individual cell in our bodies carries a tag that identifies it as a part of us and tells our immune system not to attack it. Possible threats such as bacteria and viruses lack these tags and are therefore targeted by our bodies' defences. However, unless you have an identical twin (in which case rejection is not a problem), the tags that our immune system



recognise are different for each of us. This means that a transplanted organ is attacked by our own defences and rejected.

It was in the same year – 1965 – that the first drug specifically designed to suppress the immune defences in transplantation operations and tackle the problem of rejection was introduced. This drug is called 'Azathioprine' and is still in common use today.

By further coincidence, it was also in this year that the man whose research was responsible for the introduction of Azathioprine came to work in Cambridge as Regius Professor of Surgery. His name was Roy Calne and he later received a knighthood for his work.

By 1970, only 8 intestinal transplant operations had been carried out and the results were not promising at this stage. To understand the reasons for this we have to consider some of the unique features of the gut. The French call it the 'Tube digestif', but it is so much more complex than just a simple tube. The intestine is the oldest organ in the body and dates back over 700 million years of evolutionary existence, about three-quarters of the time that life has existed on the planet. Evolution has tinkered with the gut over this vast period of time during which there have been two major conflicting pressures on it. Firstly in order to absorb all the nutrients from our food it needs to be reasonably 'leaky' and to have a large surface area across which the chemicals can pass. If you were able to unravel all the folds of the human intestine and spread it out, it would cover the size of a whole tennis court! However whilst this works well to allow the nutrients into the body, the problem is that it potentially makes it easy for microbes such as bacteria to invade. The gut has developed many mechanisms to resist infection over time, but as a result it is packed full of cells involved in immune defence reactions and the 'tags' that distinguish 'friend' from 'foe'. This makes a transplanted gut a good target for the body's immune defences and very prone to rejection. However, if even a little damage is caused to an intestinal transplant organ by immune attack, it makes it more leaky and allows bacteria to cross over into the blood stream. Whilst we now have powerful drugs or 'immunosuppressants' that reduce the body's ability to reject organs, the downside is that they also reduce the body's ability to fight infection. It is this balance between rejection and infection that has made the intestine more difficult to transplant than any other organ. . .

During the 1970's and early 1980's few attempts were made at intestinal transplantation. As well as the complexities of the operation and the poor results at this time, there was little requirement for it. Parenteral

nutrition was now available and patients with intestinal failure could be supported well at home and with a good quality and expectation of life.

It was again Roy Calne, in Cambridge, who opened up the possibility of successful intestinal transplantation with the introduction of a more powerful immunosuppressant drug called 'Cyclosporin' in 1978. Over the following 10 years about 35 patients in the World underwent this operation, and patients were surviving for a longer period of time thereafter – some of these courageous people are still well and free of parenteral nutrition today.

However, rejection was still a major problem. In the 1990's a new, yet more potent drug called 'Tacrolimus' was introduced and it was in 1992, that Roy Calne used this medicine for the first intestinal transplant operation in the UK here in Cambridge. Intestinal transplantation is now a routine operation and over 1200 such procedures have been carried out worldwide.

In 2004, major structural faults were found in the fabric of the dome and library of New Hall College. Whilst mediaeval Cambridge (that had remained intact for centuries) looked on, this forty year old structure had to be almost entirely rebuilt to prevent catastrophic collapse. The 'New' is clearly not always better – or necessarily even as good as – the 'Old'. As far as intestinal transplantation is concerned, the new intestine appears to function perfectly well in most cases, and the majority of patients who have successfully undergone the operation are free of parenteral nutrition thereafter and experience a good quality of life. In some patients however, the rejection process can be gradual and cause malfunction of the transplanted gut over a longer period of time that can result in a requirement for removal of the organ or re-transplantation.

Having met many of the challenges of intestinal transplantation, current problems revolve around deciding which patients would be most likely to benefit. Because there is a risk involved with the procedure, it is not yet ready for patients as an *alternative* to parenteral nutrition, and because parenteral nutrition is so effective relatively few patients really need a transplant. At the moment, it is only considered for those patients who have irreversible failure of the intestine and are having major problems with their parenteral nutrition.

Whilst Cambridge has a particular interest in Intestinal Transplantation and has close links with the intestinal failure unit at St Mark's Hospital in London, there are other units in this country where the operation is carried out – in Birmingham Children's Hospital and in St James' Hospital in Leeds.

Finally, I would like to commend Carolyn on her choice of date for this meeting, preceding the start of the Soccer World Cup by one week. However, whilst you wave your England flags and cheer, spare a thought for where it all started – here in Cambridge at Trinity College where the rules for Association Football were agreed in 1848.!!!

Dr Jeremy Woodward
Consultant Gastroenterologist
Addenbrooke's Hospital,
Cambridge

We would like to thank you all very much for a pleasurable day at the AGM in Cambridge. It was a good turnout, very well organised, and the programme was enjoyable with a lot of interesting information and all presented with a sense of humour which was lovely. It was so nice to be with people in the same or similar situations and who understood. It was great to meet the girls from Calea who we speak to regularly and to now be able to put a face to their names.

Thanks again for a lovely day – and the early morning was definitely worth it. We look forward to the next time we all meet up again.

Tracy Hill and Lisa Jackson

"I had to laugh a little about everybody calling Dr Woodward 'Jeremy', while I call him Dr Woodward – and quite rightly, because I am a patient of his."

Judy Jolly

"The best bit was meeting people with similar problems to me, talking to them and comparing experiences. This was as good as any talk on the psychological aspects of artificial feeding. It was a good relaxing location for me too."

Chris Turner

"I really liked the day in New Hall. I was surprised at how many people there were who could eat normally – perhaps they have a different underlying condition to me."

Judy Jolly

This is to say thank you to all the organisers and contributors of the AGM. We very much appreciate the hard work which went into making it a well organised, informative and a sunny (we would like to know how you managed this) fun day in a historic setting. We thoroughly enjoyed the day, including the return walk to Cambridge station via the hustle and bustle of the town centre.

Jennifer and Anthony Collins

It was a pleasure to host this year's meeting and I would like to thank Carolyn, Lee, Justine and Brian for their support with the arrangements and the rest of the EC for attending and giving their time and support. I feel certain that the venue gave everyone the feel-good factor which contributed to the overall success of the day.

Jackie Huff

Barbara Berry spoke about the ups and downs of living with a long term medical condition. She talked about life before diagnosis, the years between diagnosis but prior to PN and concluded by describing the transformation this treatment has made to her life.

"... Six months later I found myself back at the Queen's Medical Centre in Nottingham with a new consultant and within five minutes of meeting him, he'd spoken those magic words 'Quality of Life'. I knew from that moment onwards that things were going to be different. Here was a consultant who based his treatment on his patient's quality of life, rather than what the scales registered. He talked to me about TPN and suggested I go away and give the idea some consideration. I left hospital that day with something I'd never had before – hope. And although it took another year for me to be assessed and finally started on TPN, just knowing that there was the possibility of treatment on the horizon put the enthusiasm back into my life.

Some people want a sympathetic doctor, but I think empathy is a much more valuable quality for any doctor to have. What we all need is a doctor who can empathise with his patients – who can put himself in his patient's place and really imagine what it's like to live with their symptoms on a daily basis. And I think that's how come I've made it here today – because my consultant really understood what it must be like to live the way I was living every day – and he was prepared to do something about it. Yes, he warned me about all the risks involved with TPN, and he warned me that it wasn't a cure, but I think he understood the poor quality of life I had, and could see that the improved quality of life this treatment would give me was worth the risks.

And he was right, and in my mind I thank him every day – and so do my family – because we believe in the ripple effect. When a doctor, or anyone else, does something that affects someone's life, it's not only that person's life that's improved but those of their family and friends and also everyone else that they then go on to touch in their own small way."

Meet John-Luke. Teresa spoke about the difficulties of caring for John-Luke, her eleven year old son, who has complex needs including microcephaly, epilepsy and global developmental delay. He can't walk or talk, is in a wheelchair and is fed by gastrostomy. She spoke about the lack of continuity of care and information she encountered, poor organisation, the difficulties caused when given conflicting advice and the need for better community services. . .

"First Contact (not ET, EN!)

On admission to hospital at 6 months old due to 'failure to thrive', John-Luke developed gastro-enteritis and was put on a drip, eventually coming off but having to go on to feeds via a naso-gastric tube when everyone noticed he would not have more than 1 oz of milk at a time. This was our first contact with enteral nutrition. During the eight weeks John-Luke was in hospital, I also stayed there and noticed that protocols were not always followed. I also had different advice given by nurses on every shift – the use of different sized syringes for example. Having to decide between opinions was very stressful and any decision was only met with comments at the next shift that I was doing it wrong. It would have been easier to have official training following some kind of national standard, then we would all be singing from the same hymn sheet.

Infection Control

Once home, John-Luke had bouts of illness every few weeks, and so we were regulars at the local hospital. Bins on isolation units must be emptied by cleaners wearing gloves but on one occasion I saw a nurse perform this task – no gloves – then she proceeded to take a full bottle of milk to a baby without having washed her hands! I highlighted this, much to the dissatisfaction of the nurse!

I want, I want, I want. . .

Feedback both ways between professionals and parents/carers could certainly be improved. We all need to talk (and play) together, and follow the same protocols, and having full time community paediatric nurses available would mean a lot more peace of mind for some of us. And, for some, problems with enteral feeding are only the tip of the iceberg. I still have many things to sort out which crop up regularly every year including all the associated paperwork and equipment issues related to John-Luke's needs. Somewhere we have to fit in leisure. And of course our children with special needs also need to have a life of their own, with some kind of activity where they feel welcome.

And it's organisations like PINNT that provide a lot of support to parents like me, and who can talk on behalf of children like John-Luke who can't speak for himself, except perhaps occasionally to say 'yeah'!"

READERS' EXPERIENCES

I have been very sickly all of my life and have always been very slim. I had bouts of illness where I dramatically lost weight but was told my stomach symptoms were due to the medication I was taking for my asthma. Three years ago I had another period of being unwell and being unable to eat. I was asked on a number of occasions if I was anorexic and when I again denied this, the gastro consultant decided I had irritable bowel syndrome.

After more than a year of living on Ensure Plus, despite no referral to a dietician, I decided to stop drinking it to demonstrate how severe my symptoms were. I lost 4 lbs in less than a week and was admitted to hospital. After 5 weeks as an inpatient, and further denials of anorexia, I had a PEG-J fitted (the feed bypasses the stomach and is delivered into the intestines). I was told that this would be a low profile button and that it would only be in place for six months, neither of which were true!

When I was discharged the dietician gave me the contact details for PINNT. I decided not to phone PINNT as I thought its members would all be old people who couldn't eat due to medical conditions brought on by the ageing process! After I'd had the PEG-J fitted there was no attempt to discover why I couldn't eat and was in pain; and despite not having any idea what was wrong with me there was no referral to another doctor. In desperation my mum phoned PINNT and spoke to Carolyn, who was a breath of fresh air! She was not the old person with too much time on her hands that I imagined PINNT members to be.

PINNT's help has been invaluable and I wish I'd phoned sooner. . .

After listening to my story and reassuring us that we weren't alone and that the situation would improve, Carolyn used one of her many contacts to get the name of a consultant who dealt with these illnesses. Ironically he worked for my NHS trust and was just half an hour down the road.

Dr Travis diagnosed my problem within weeks (severe dysmotility syndrome or pseudo-obstruction) and referred me to the pain clinic. The combination of medications I take now have the pain under the best control I've had for years. Although I'm not able to work more than a few hours a week, I've regained some quality of life and even have a social life now.

PINNT's help has been invaluable and I wish I'd phoned sooner. I now try to go along to regional meetings and AGMs as it is very reassuring to be able to discuss my situation with people who understand the implications of it.

I spoke to Carolyn at the AGM in June and asked whether more information specific to people on PEG and PEG-J feeds could be made available. PINNT would like this to happen, but this needs to be 'fed' back to PINNT by those of us on enteral feeding. I'd love to hear from other people with PEG/PEG-Js and discuss the issues that are relevant to us. We can then inform the PINNT team as to what information we need, and be involved in its production.

Karen Williams

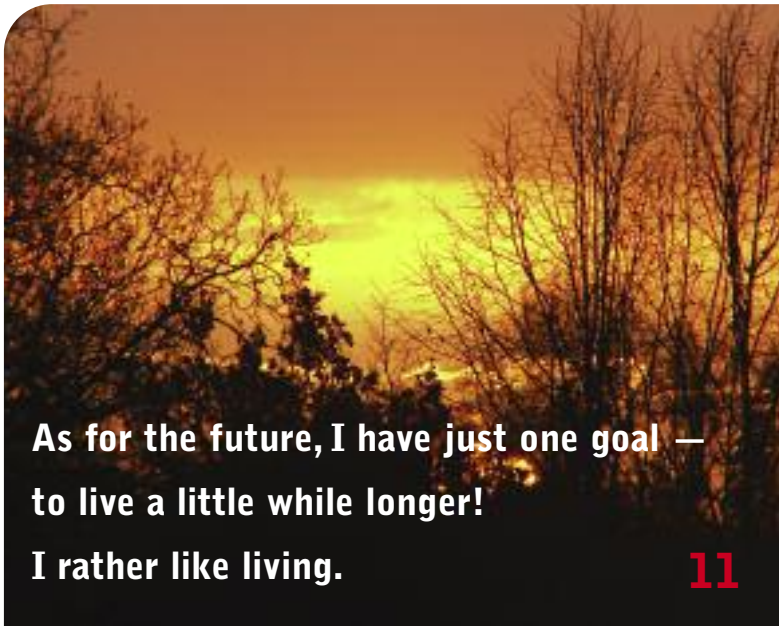
Ed replies: A golden opportunity here. It's your chance to tell us what information you would like. We are here to facilitate information that will help you in educating others about your needs. . . Come on, don't sit back, write to us *now*!

I have been enterally fed due to scleroderma and swallowing problems since Christmas 2005. I am 75 years old and my children and six grandchildren all live abroad, in Holland, Aruba and Canada and this was where I planned to go and live too. However, by the time I had bought a house and arrived in Canada, my scleroderma had broken out all over the place and following four hospitalisations, the Canadians refused to allow me to settle there. I don't blame them. I sold my house and came back to England where I am surrounded by good neighbours and friends and receive excellent medical treatment. I have lived here for thirty years now, although I still have my Dutch passport! The diagnosis of scleroderma was made last year, although the doctor told me I must have had it all my life. This came as a complete surprise to me.

I do manage to travel now and again including short trips to Venetia and Holland, and in general I feel that I cope well with my feeding and I am well supported by my dietician. My main concerns at the moment are faecal incontinency and frequent TIAs and I would welcome any contact with others in a similar position.

As for the future, I have just one goal: to live a little while longer! I rather like living.

Judy Jolly



REGIONAL REPORTS

Welsh Region

At last we managed to have a meeting on 13 May at Singleton Hospital, Swansea. The meeting went well with 26 people attending. New HPN patients came and I think they enjoyed their visit, hopefully benefiting from talking to long-term patients.

The nutrition nurse from UHW Cardiff, Winnie Magambo, explained who was part of the Welsh network: University Hospital of Wales, Cardiff, Singleton, Swansea and Wrexham Maelor hospitals. She spoke about a new initiative they had started – a Medic Alert card. It is small enough to carry in a wallet/purse and informs the reader that the carrier is on HPN, and it gives the phone number of the Nutrition Support Team etc. On the reverse it describes what should be done if the line is infected. This will be very useful when a patient is rushed to their local hospital as an emergency, where care of HPN patients is unfamiliar. Next to speak was Catherine Morgan-Edwards, Nutrition Nurse Specialist, Singleton Hospital, Swansea. Local patients were reassured to know there was local expertise. She said that the nutrition team was being formed and that once the team was fully functional, holiday and sickness cover would be available. Personally I found it very convenient: when blood is needed from the line and arm to test for bugs it was so easy to slip to the hospital nearest to my home (five minutes) instead of an hour travelling on the motorway when feeling unwell.

The Nutrition Nurse Specialist at Wrexham Maelor Hospital is Paula Edwards. I hope to meet Paula in the near future and introduce her to PINNT. I am sure patients in North Wales know her well. Perhaps we can hold a meeting in the Wrexham area in the near future?

The last speaker was Beverley Young from Calea. Beverley talked about pumps and answered questions about patient concerns. Mandy O'Connell, a Calea nurse for the South Wales area also contributed to a session answering members' concerns. Calea said they welcome visitors and anyone interested should contact them. Finally, general questions were thrown at the speakers and we chatted among ourselves until the meeting finished at 4.15 pm. I was sorry to see that there was only one enterally fed patient at the meeting though. It would be nice to see more NG/PEG patients as I am sure it would be helpful for them to discuss any problems they might come across.

In the letter I sent out inviting members to the meeting I mentioned that Winnie was asking for volunteers to represent patients at the Welsh HPN Network Commissioning Group. Again meetings will be held half-yearly, the last one being on 6 July 2006 in Cardiff. Winnie had a good response from a few members. Could anyone who is still interested in volunteering please contact Winnie.

Lastly, I mentioned at the meeting the Expert Patient Scheme. You may have seen flyers about the scheme at your surgery or hospital. I had brochures for the Cardiff group but none for the Swansea group. However, if anyone wishes to know more about it, let me know and I will send you details of meetings etc.

Our next meeting will be in autumn/winter. Has anyone any suggestions as to where they would like it to be held or any particular speaker they would be interested to hear from?

Letty Johns

Scottish Region

I can personally say it was so great to all get together again. Unfortunately because of Samuel being unwell, I had to cancel the March meeting, but we all enjoyed getting together again and it is amazing just the boost that you receive from seeing members again. Everyone was talking and discussing their experiences of the last six months. I want to encourage others to attend meetings. I know that it is not always possible due to circumstances and health but if you can go along I guarantee you will feel better when you leave.

Thank you to the members who came along for the first time to Glasgow. We look forward to seeing you again and your input was great.

Although I am the regional co-ordinator for Scotland and I know the other co-ordinators will agree, it takes all of us to make PINNT work and the encouragement you will find will make you too want to help.

Sharon Bell

REGIONAL CO-ORDINATORS

East Anglia
Jackie Huff 01767 225631

Scotland
Sharon Bell 0141 959 6701

Northern Ireland
Raymond Toulson 028 9260 4705

North of England
John Sturt 0191 565 8651

Wales
Letty Johns 01792 521618

SPONSORED WALK

Forth Road Bridge, Edinburgh: 14th May 2006

When I read about Jennie Maughan's sponsored walk in the February edition of Online I thought 'I could do that' and I asked my two granddaughters, Emma 12, and Rachel 8, if they would like to help me. Before I knew it, what started out as a short stroll soon blossomed into a four-mile trek across the Forth Road Bridge and back again.

PINNT supplied sponsorship sheets and laminated 'Walking for PINNT' logos to pin on our t-shirts and Carolyn even made a special logo for my toy poodle, Misty. Now all I had to do was find people to sponsor me.

I came up with 26 names and places and handed out my sponsorship sheets to them. Most people were more than happy to help, but of course I did get the odd refusal. But did I let this get me down? No! I was determined to do my best for PINNT so even when my request was met with less enthusiasm than I had hoped I didn't give up – I left the form anyway and my determination paid off – I collected an extra £27 from organisations that had initially said they were unable to help. I even collected £5 from the N Power engineer when he came to change my gas and electricity over. I was on a roll.

My twin brother owns his own company and although I had to tell him word for word what to say (he's never asked people for money) he's collected £200 with more to come.

The day arrived, dry and chilly, and ten walkers gathered at the start, along with Misty in her custom-made outfit. I was unable to walk as I had fallen a few times and have problems with my hips but I waved them off as they began their trip, armed with crisps and juices and a smile on everyone's face. Some cars tooted and that spurred them on. Just as they crossed the finish line an hour and a half later, a few drops of rain began to fall – how was that for good timing? Everyone agreed that they had had a wonderful time and I would like to say a big thank you to everyone who helped me raise so much money. I couldn't have done it without you. In total we raised £1348.00.

I hope now that someone will read my story and decide to give it a go too. You don't even need to be able to do the walk yourself in order to help PINNT – you just need to be a good organiser. Write down a list of friends and organisations that might help and hand them a sponsorship form - your enthusiasm will do the rest.

Enis Nichol

Ed replies: Well done Enis. It is fantastic that through reading Jennie's article you too were inspired and arranged your own sponsored event for PINNT. As you said at the AGM, you don't have to actually do the walk yourself, just find people to do it for you and raise funds – excellent! Thank you – we continually need people like you to keep our Treasurer happy!

TPN

What's the big deal? You just drink the stuff!

Today I had a meeting with the Occupational Health doctor who has lots of letters after his name. Half way through the interview he tells me he sees many patients on TPN. I just stared in stunned amazement and I sarcastically said 'Well, that's strange, because according to the new PN register there are just over 10 of us here in all of New Zealand!'

He goes on to say he also visits hospital patients in two other districts and sees PN being given all the time. Then I realised he hadn't a b****y clue, because he goes on to say, 'The nurse hands it out and you just drink the stuff!' I would have bashed my head on his desk, but I already had a headache from the TPN!"

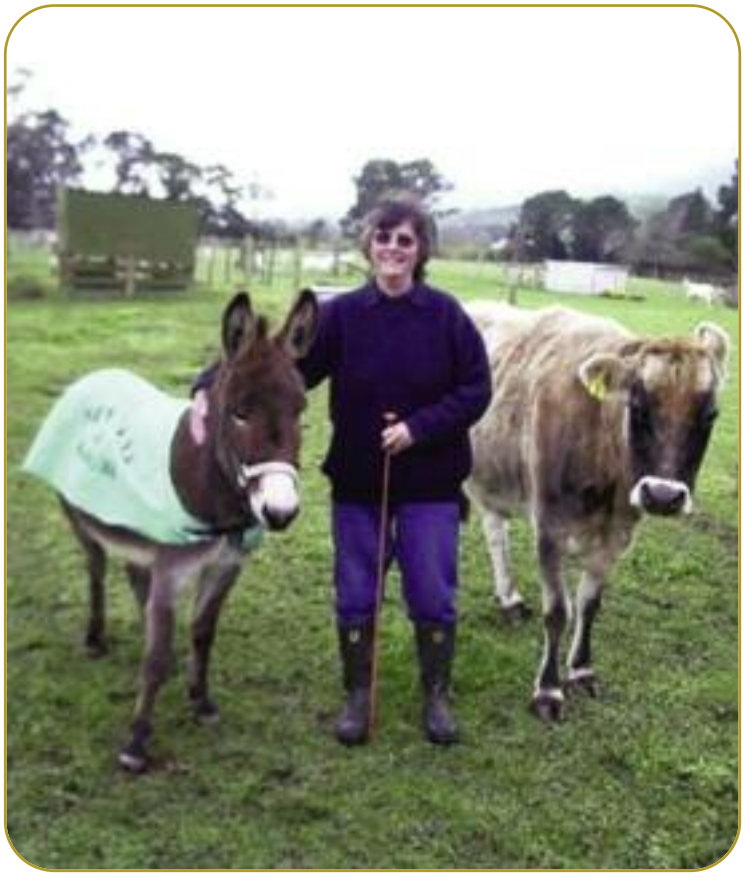
This humorous but poignant story from one of our New Zealand (NZ) HPN patients illustrates the constant need for Education, Education, Education. No doubt many PINNT members will have experienced similar examples of such 'educated ignorance' and may be able to advise our Kiwi friends on the most appropriate and diplomatic ways of handling such situations.

HPN is not that new in NZ. The first patient was trained to go home in the 1970s by Dr Jack Havill at Waikato Hospital and she remained on HPN for over 29 years. Professor Graham Hill (ex Leeds General Infirmary) and his Auckland team further developed a training programme during the 1980s, but partly because of our small population and the relatively long distances between the major hospitals and where people live there is still much less home care than in the UK. Consequently there is not yet a support group for HPN or HEN patients. At the recent PN workshop organised by the Nutrition Support Team at Auckland City Hospital, I led a session on 'HPN from the patient's perspective'. I began by reviewing the activities of some European HPN patient support societies; how they function and how they have created a contact network with similar societies abroad.

I then explained how, over the years, PINNT in the UK has not only brought together and supported patients from all over the country, but also doctors, nurses and other healthcare professionals working in the field of artificial nutrition worldwide.

Then I introduced the 'stars of the day'. First by video link from the UK, Carolyn Wheatley, Chair of PINNT remembered starting on PN more than 22 years ago, and described the early days and experiences with PINNT and the importance of the regional groups and get-togethers along with the information provided to members on a wide range of subjects. Carolyn offered her personal encouragement to the 'Kiwi' patients and their carers in their efforts to establish a support group, ending her greeting from across the globe with the comment "Don't ever forget – we are people, NOT numbers."

Following that, Brenda, a HPN patient and part-time farmer from Waikato, needed no further encouragement to describe the pain, lethargy, reactions and personal challenges during 6 years on HPN. "PINNT saved my life," she



declared, explaining her problems in the past and the threat of losing her ambulatory pump that lead her to reading PINNT's Online magazine which included information that supported her successful argument to continue with the 6060 pump, which she is still using today. She also emphasised the need for social acceptance, for adaptation and for a changed attitude to work, to peers and to strangers and also spoke about her frequently failed attempts to suppress annoyance at being told "But you look so well." Brenda did indeed look well and performed exceptionally as 'the human face of PN'. Her comments and positive attitude motivated us all, but gave us much to think about for prevention of complications and future planning of HPN patient services.

We have a plan to organise a branch of PINNT 'down-under' so any help, advice and encouragement that all you experienced Brits can provide will be much appreciated.

Many years ago, I was privileged to help the St Mark's team develop the facilities, equipment and training programmes that enabled the very first UK HPN patient to go home. I have been an active member of PINNT since its very early days and have made many dear friends in your organisation from whom I have learned a great deal. PINNT has always motivated me to think carefully about the role I play in helping people on HPN – the UK experience has reached far and wide. Keep up the good work, support your group and help us "down under" to learn from your excellent example.

Professor Gil Hardy
Oxford Nutrition and Auckland University

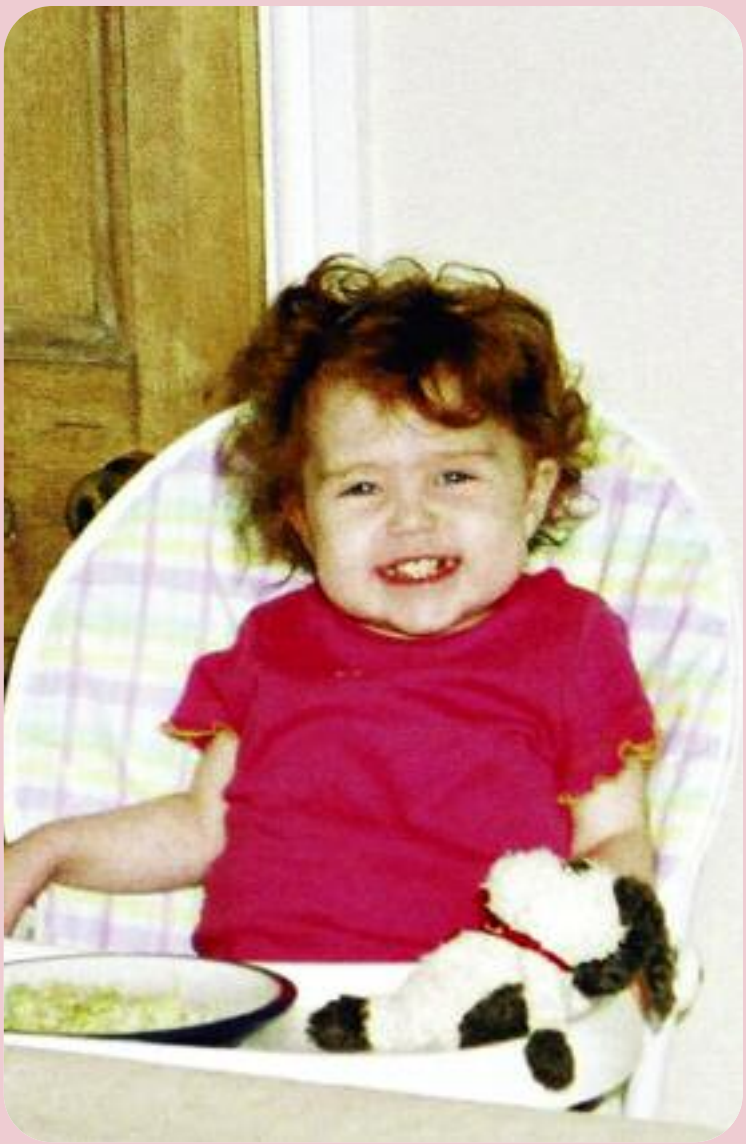
Alice Edie Taylor

At 3.30 p.m. on Monday 7th August our daughter Alice died in our arms peacefully and without pain. She had been critically ill for several days as a result of abdominal sepsis which caused septic shock and ultimately organ failure.

From a cherubic baby to a playful toddler Alice delighted us and brought out the best in her father and me. Alice was very sociable and thrived on contact with people. Our family often travelled great distances to spend time with her and her weeks were filled with social engagements. She enjoyed books and music and during recent weeks developed a passion for playdough! She loved her toy dog who went everywhere with her and is with her even now.

Against expectations Alice had begun to enjoy eating small amounts of particular foods and found great enjoyment in this. Her favourites were banana, rice, crisps, peas and lettuce!

Things were not always easy for us – far from it. Alice's medical condition meant that the first eight months of her life were spent at the Queen's Medical Centre in Nottingham and at Great Ormond Street. Her condition was rare and a diagnosis took many months to come and many more for the full implications of that diagnosis to hit home. Attempts at feeding Alice were unsuccessful and we had no alternative but to accept the responsibility of feeding her at home intravenously.



And when we are struggling we will remember what Alice taught us. That life is short and precious. That there are things to fascinate us wherever we look. That happiness and peace can be found by living in the moment. That life and people are good.

Managing Alice's condition and keeping her well was a huge responsibility. We had many sleepless nights and long days spent in hospitals. We learnt to live with the threat of liver failure or sepsis caused by infection but as time went on and Alice thrived we began to be able to push these things to the back of our minds.

We walked a tightrope between life and death but we always looked to the side of life and whilst we ultimately fell to the side of death we were right to look to life.

Throughout this journey we were sustained and strengthened by our wonderful family whose love for Alice is deep. They and our friends enabled us to live the 'normal' life we wanted. A life of walks and play, trips to the zoo and mother and baby group. The life any little girl might expect to have.

But this could not have been achieved without the support, resources and sheer brilliance that we found in the NHS. We have always been able to get everything we needed for Alice and to her dying breath never ceased to be amazed at the calibre of the doctors, nurses and support staff who helped us. We will miss them.

We are rich in this country and do not have to experience the pain that parents in other places in the world must feel at not being able to get medical help for their children. It is for this reason that the collection in Alice's name will be for 'Doctors Without Borders'. (www.justgiving.com/aliceedie)

Alice's death was painless and dignified. She only knew the love that surrounded her as our voices reached her in her dreamlike state. It is us who must find a way forward and face the gradual unfolding of the realisation of all that we have lost.

And when we are struggling we will remember what Alice taught us. That life is short and precious. That there are things to fascinate us wherever we look. That happiness and peace can be found by living in the moment. That life and people are good.

Thank you Alice. We will always love you.

Jo-Christa Taylor

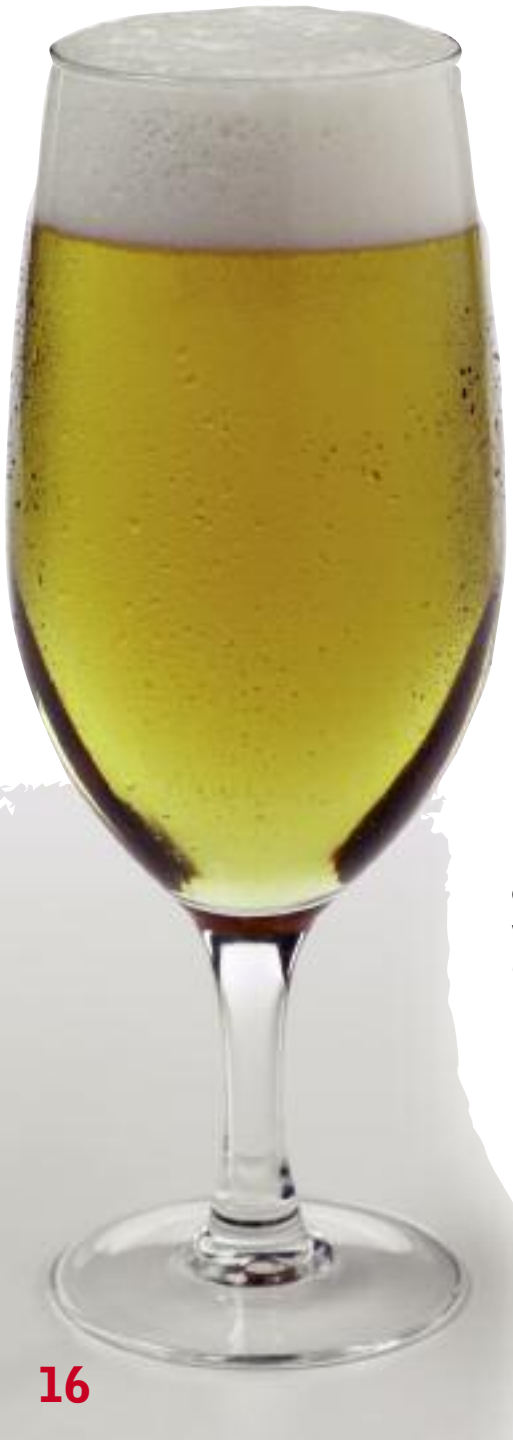
IS YOUR GLASS HALF FULL OR HALF EMPTY?

The Optimist

What do we have on the optimist's cliché conveyor belt today? Ah yes. . . a light (for the end of the tunnel), a silver lining (with a cloud on top), a pair of spectacles (you guess the colour) and the obligatory half -????? glass of beer (you supply the missing word).

I'm a half-full man myself. Always have been. Having the right blood group helps – mine is B positive! I think most people are 'programmed' to be sunny or glum pretty early on in life, don't you? It sort of colours their outlook on things.

Don't get me wrong – we all have moments of gloom and despondency. I do, and I don't always keep them to myself either. It's all right to feel angry, exhausted, cheated, even despairing from time to time. Especially with the health issues that you and I have. The thing is. . . what do we do with them?



It's hard not to feel resentful when you've lost a fulfilling career because of ill-health (and the income and perks that go with it); or you can't eat like 'normal' people; or you've spent more time in hospital than the nurses; or the pump alarm's just gone off for the sixth time that night.

I've been there – I own the T-shirt. Yet I've come to realise that what I have far outweighs what I've lost.

I refuse to be defined by my health/medical condition. This is not the sum total of my life, it's a part of the many blessings of my life. If you think that is yet another cliché to add to the collection, then think again. Is that a chip beginning to wear a groove on your shoulder?

When I look at myself in the mirror I see the bag, the line and the scars but they don't depress me. They're my lifeline and without them there would be no image in the mirror – no laughter, no music, no friends or family to enjoy.

This is how I see myself – fortunate to be around and determined not to be anyone's patient. No room in our home is a hospital ward or doctor's surgery. You will not see any equipment, dripstand, medical supplies, ileostomy gear or medications anywhere unless you open a cupboard or a drawer. When I run the PN at night the rucksack is on the floor by the side of the bed – nothing else.

My wife has read this and says I'm beginning to sound evangelical and I should tell you what a tough time I've had. But we all have, haven't we? Sometimes I am so tired that I can only lie down on the couch. But that's cool – I listen to music, the radio or cuddle the dog.

Being an optimist I've always assumed that things will get better – even when they've got manifestly worse. Yet since TPN, life has been good. I've met a whole range of fascinating people in voluntary and community roles; we've managed to go abroad a number of times and I count each day and value the small victories that each day brings.

I'm writing this on a sunny summer day in the garden. It's warm – the birds are singing (no really!), the flowers are in full bloom; and I have a glass of beer by my side – half full of course!

David

The Pessimist

It's not that I don't want my glass to be half full – I do, really I do – it's just that whichever way I look at it, my glass is always half empty. There's so much missing from my life that it's hard to see things any other way.

I miss my social life. I can no longer join in when my family or friends go out for a meal. Yes, I sit at the table with them, my plate of 'play' food in front of me to give the impression that I'm part of the party, but the reality is that it's not enough. I want to taste the food and join in the discussion about whether the steak was cooked to perfection or was as chewy as old leather, or whether the pastry on the apple pie was light and flaky or hard enough to crack teeth. How can I do that when all I can swallow are a few spoonfuls of soup and some mashed potato?

Then, as the evening mellows and the alcohol flows, I'm missing out again. My gut can't take the booze (and even if it could it wouldn't mix with the medication) and the nearest I'll get to wine is the exasperated whine in my voice as I politely refuse yet

another offer of a drink. Sometimes I feel like a social leper as I find myself constantly saying no to offers of food and drink. It's not that my friends don't understand that I can't have it, it's just that in their own way they feel bad on my behalf and mistakenly think that by at least offering me the goodies, this will make up for not being able to actually have them. But, as anyone who can't eat and drink will tell you, it doesn't. As the evening wears on I begin to stick out like a sore thumb. Their mood changes but mine doesn't. They're all becoming pleasantly tipsy, whereas I remain as sober as a judge. The sensible one! The designated driver! That's if I don't have to leave early to fit in the twelve hours on my feed.

I'm a slave to machinery and the clock. Yes, I can adjust my feeding time and connect up at midnight after a 'fun' night at the pub, but then I'm hooked up to a pump until midday the next day. It's just not natural: I feel like my freedom has been taken away from me.

On the one hand my treatment enables me to live my life (sorry, a positive thought just crept in there!) but at the same time it comes with a list of complications and life changing adjustments that I need to take into account.

But I think I've been labelled wrongly. It's easy to throw the word 'pessimist' at someone when, in effect, they are simply being a realist.

Realism means acting with safety and caution and trying to protect myself from things that can hurt me. On the practical side, this means facing the prospect of infections and making sure I follow a strict procedure to keep this risk to the absolute minimum. Socially, I am cautious when it comes to striking up relationships for fear of being rejected. It's hard enough for anyone to take those first steps in a loving partnership, but how much harder is it to introduce yourself *and* a line? At what point do you raise the subject, and what's the best way to go about it? It's not something you can casually drop into the conversation.

Is being a realist such a bad thing anyway? I'm prepared for setbacks and I know my limitations. I don't set unrealistic goals and try to live up to other people's expectations. I don't pretend to myself and others that life is just one big holiday. It's not. But being a realist can be a good thing. I'm rarely disappointed because I don't expect too much to begin with. Most of all, realists can still be open, loving, caring, humorous people.

I'm sitting in the garden on a scorching hot day in summer, the wasps are pestering me and the pollen is making me sneeze. A couple of minutes ago I reached for my glass of lemonade and knocked it over. I grabbed it just in time, but, as usual, it's now half empty.

Mary

Carrots, Eggs and Coffee

Whether you're an optimist or a realist, you'll never look at a cup of coffee the same way again. . .

A young woman went to her mother and told her about her life and how things were so hard for her. She did not know how she was going to make it and wanted to give up. She was tired of fighting and struggling. It seemed as one problem was solved, a new one arose.

Her mother took her to the kitchen. She filled three pots with water and placed each on a high fire. Soon the pots came to the boil. In the first she placed carrots, in the second she placed eggs, and in the last she placed ground coffee beans. She let them sit and boil, without saying a word.

In about twenty minutes she turned off the burners. She scooped the carrots out and placed them in a bowl. She pulled the eggs out and placed them in another bowl. Then she ladled the coffee out and placed it in a third bowl. Turning to her daughter, she said, "Tell me what you see."

"Carrots, eggs and coffee," she replied.

Her mother brought her closer and asked her to feel the carrots. She did, and noted that they were soft. The mother then asked the daughter to take an egg and break it. After pulling off the shell, she observed the hard boiled egg. Finally, the mother asked the daughter to sip the coffee. The daughter smiled as she tasted its rich flavour.

The daughter then asked, "What does it mean, mother?"

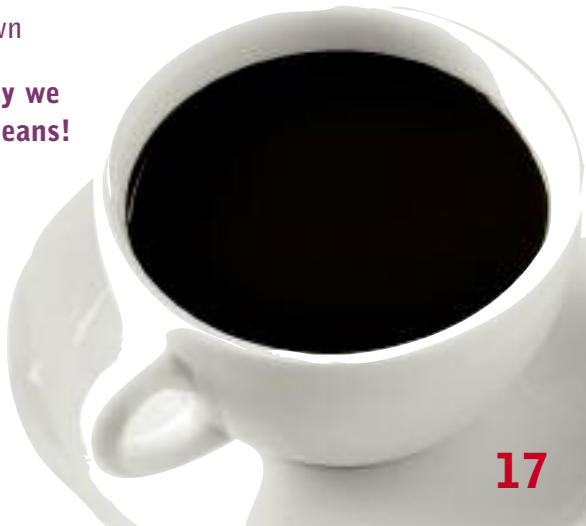
Her mother explained that each of these objects had faced the same adversity – boiling water. Each reacted differently.

The carrot went in strong, hard, and unrelenting. However, after being subjected to the boiling water, it softened and became weak. The egg had been fragile. Its thin outer shell had protected its liquid interior, but after sitting through the boiling water, its inside became hardened. The ground coffee beans were unique, however. After they were in the boiling water, they had changed the water.

"Which are you?" she asked her daughter. "When adversity knocks on your door, how do you respond? Are you a carrot, an egg or a coffee bean?"

Author Unknown

Ed replies: May we all be coffee beans!



POST ROOM

I was interested to read Chris Turner's letter in the June edition of Online. I can sympathise with him and his problem with overnight feeding. I spent several years propped up on a pile of pillows until I realised – after another stay in hospital – that it is possible to buy adjustable beds for use at home. I bought a Dunlopillo electric adjustable bed which has greatly improved my quality of life. It is possible to adjust it to almost any angle including upright and it isn't difficult to sleep in. They are quite expensive but I bought mine in a sale.

I wonder if any of your readers share a problem I recently encountered. I have been on enteral feeding – one year via a PEJ and then via surgical jejunostomy – for seven years. For that time I have been using a MIG tube and a Patrol pump at night, and a ClearStar pump during the day. A few weeks ago my nutrition team changed the whole system, giving me a Flocare tube and Flocare Infinity pump. The problems began almost immediately with severe right sided pain and copious quantities of bile pouring out of the tube, together with severe nausea. At times the force of the bile pushed out the connecting piece on the giving set. After a very worrying fortnight I persuaded the team to change the system back to the original and within hours the problems were receding and within a day I was back to normal. My husband commented that it was a case of "if it ain't broke, don't fix it."

Anne Peck

Another excellent edition of Online – it seems to improve issue by issue of late – thank you. I was fascinated to note that in the three items from PEG feeders they all feed by day, two of them citing the reason that it is necessary to be in a semi-upright position to take in their feeds safely. For various reasons I also feed by day. I have to sleep in a semi-upright position otherwise I tend to have problems with my breathing, and I have also had problems with recurrent persistent vomiting. When I first had my PEG I was told to feed at night, and it quickly became apparent that this was not for me. The dietician got a bit huffy with me when I said that I was switching to a daytime feeding regime, remarking that night time feeding was the norm. It's interesting to see that I'm far from alone regarding day versus night time feeds. Daytime feeding seems so much more natural to the digestive system.

Thinking on it as I write this, they weren't consistent in their instructions. When I was hospitalised for a time, a two hour trip to day surgery for a supra-pubic catheter to be fitted (joy of joys: another tube!) resulted in emergency surgery and a two week stay as they had misplaced the catheter such that urine, instead of flowing out through the catheter, was flowing into the peritoneal cavity. I was permitted no feed via the PEG for about a week, after which the nurses, on the instructions of the dietician, started setting the feed during the day, possibly because the pump (I wasn't allowed to bring my own) was the oldest, noisiest, most inaccurate and temperamental machine they could find, with an alarm that kept going off, and would have kept the entire ward awake at night.

Once again, thank you for an excellent and informative edition of Online.

Melanie

During last summer when my PN was delivered I noticed that when the bags were taken out of the delivery ice boxes, the feedbags were not as cold as they were when I take them out of my fridge each day – actually they felt rather warm. Once the new delivery was placed in the fridge I had terrible trouble getting my fridge back down to the right temperature. It often took about 12 hours to stabilise the fridge temperature into the acceptable range. My concerns were again prominent during this summer and it has caused me to consider the safety of the feed itself.

Does anyone know if the PN is still stable if the cold chain is not maintained at the correct temperatures? What happens if the temperatures fluctuate? What happens if my feeds are on the delivery van for a long time? Usually we only get a short spell of hot weather but this summer we saw extreme temperatures. I wonder how deliveries work in constantly warmer places or countries!

Anne

Ed replies: PN should be delivered in containers that have been validated to ensure they are kept between agreed temperatures that retain the chill factor for the feeds. Each homecare company may have different types of boxes that they use. If you have any concerns then you should contact them directly to ask how long their boxes are validated for and how the packaging has been decided upon: i.e. how many ice packs per box, where they are placed etc. Some people have their deliveries made via refrigerated vans in addition to the validated boxes used for the feed. We would strongly recommend that if you are worried about the stability of your feeds that firstly you should highlight this to your homecare company or the person responsible for your homecare service. Secondly you could suggest that they monitor the temperature of your feeds for a set number of deliveries, especially in the summer if it concerns you, and see what the results show. We would welcome any other thoughts readers may have on this subject.

In response to your advert for discounted holidays through Haven, I have recently stayed at their site at Haggerston Castle on the east coast of Scotland, and I can highly recommend it. It has everything you could expect from a big site – personal service, non-stop entertainment for both kids and adults, plenty of storage space in the caravan for all my medical supplies and I was able to take my feed everywhere with me.

Sue Simpson

I do think an Internet Forum would be the way to go. I could imagine that I personally might use it quite regularly.

Carola

I congratulate PINNT on the information and support I have received in respect of the potential replacements for my Baxter 6060 pump. Rumours have been rife in the waiting room and it is evident that this piece of equipment is essential for many people such as myself for both feeding and general acceptance of my current eating habit! The portability it offered during the very hot weather enabled my extra fluids to be infused without imposing huge restrictions on my mobility. You have kindly informed us of what is up and coming regarding replacement pumps but as the time draws closer for my Baxter 6060 to be withdrawn I am beginning to be concerned. Several months ago my hospital asked me if I would be willing to try these new pumps out as soon as they became available, but I have heard nothing. Does this mean that no replacement pumps are yet available? It is not my intention to raise alarm bells for fellow readers on PN but I would like PINNT to update us on the current situation. I am also concerned that the decision regarding which pump is the most suitable will be made for me by others who may not have the same needs. Can you tell me who makes the decision about which pumps patients will eventually get – will it be the patient, the hospital or the homecare company? Sadly I am not one of those people with the talents to operate the internet.

Ed replies: We are happy to continue to pass on information that we know affects many of our members. You will see in this edition we have given a special mention to the three pump companies who kindly supported our annual meeting. There is a special sponsors' section too – this gives a little more information. We are also now aware of one other potential replacement – it is the Micrel Rythmic PN pump. Our recommendation is that anyone who may be concerned about which pump they will receive as a replacement to their 6060 should talk to their hospital/unit/team. Ideally PINNT would like to think that in the current climate of 'patient choice' you will be given a choice from pumps that have passed both clinical and safety trials. We fully understand how frustrated some of you are currently feeling when you are being told that the decision about the pump you will receive may be based on other people's opinions and not your own. There are choices coming into the market and PINNT advocate that within all the safety parameters patients should be given a choice – we have different lifestyles with individual needs and expectations – do not be afraid to enter into a dialogue with your hospital/unit/team if you feel you would like to view or try a pump that may not be offered to you. Ultimately the decision should be made by your hospital/unit/team.

PINNT PRIZ£ POT ENQUIRIES

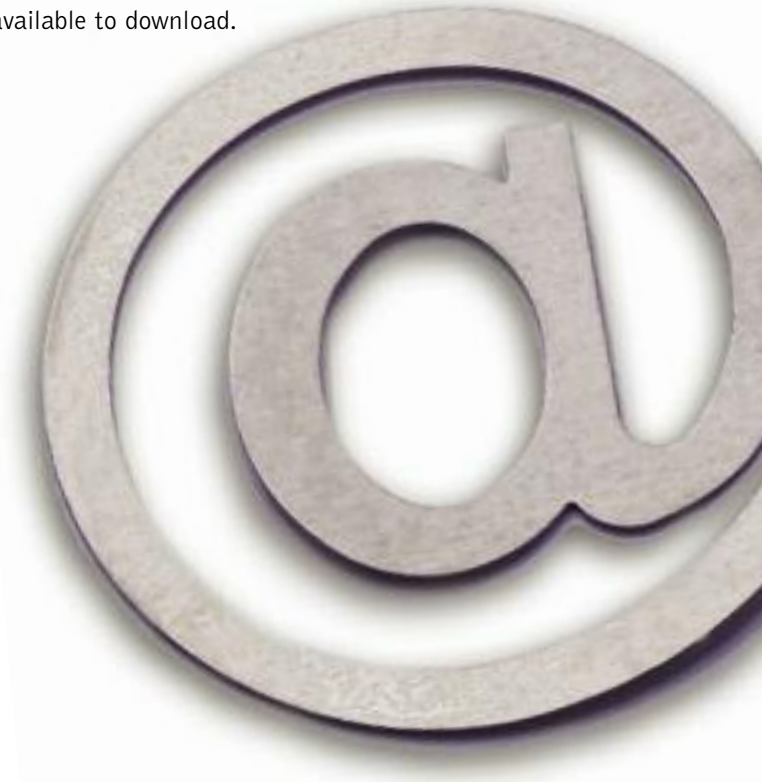
If you would like to sign up to be included in the PPP – PINNT Prize Pot, then please contact Sarah on 01322 383507 to receive an application form.

PINNT LEAFLETS

ADVICE ON CLAIMING DISABILITY ALLOWANCE AND CLAIMS AND APPEALS — available free from PINNT to members.

WEBSITE ADDRESS

Don't forget to log on to **www.pinnt.co.uk** where you can access all kinds of PINNT information, some of which is available to download.



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
Tel: 0115 849 1905
Email: barbara.berry3@ntlworld.com

PINNT:
PO Box 3126, Christchurch, Dorset BH23 2XS
Email: PINNT@dial.pipex.com
Website: www.pinnt.co.uk

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

Please put PINNT in the subject line.

Please remember when responding to letters, that other members may appreciate your advice. All letters will be printed unless we receive notification that you do not want it reproduced in Online.

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LIMITED SPACE NOTICE

Thank you to everyone who has written in. Please remember that we have limited space, so if you are not featured in this edition of Online then you will be in the next.

Please do keep the stories and letters coming.

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