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## REGIONAL CO-ORDINATORS' SURVEY

First of all we would like to thank those of you who took the trouble to return your questionnaires. We received 113 responses, with 48 (43%) having attended a meeting and 65 (57%) not.

Most people were prompted to attend because they knew they would meet others in the same position, and also for information and support. The place of venue was cited as being the main reason by 34 (30%), which stops attendance; health was also a factor. A hospital was voted by most as being the most suitable place to hold a meeting, but many consider patient homes, public houses, hotels and village/town halls all suitable. Saturday afternoon with an informal content was the most popular choice for time and approach.

There was an overwhelming number in favour of speakers, and suggested topics were mainly PN and EN centred, with equipment and holidays proving the area that most are interested in. Medical representation was considered necessary by 24%, whilst 70% wished it only sometimes. Most people wanted industry to be present. A raffle was supported by most (90), and the majority wanted refreshments and would be willing to contribute.

### General Comments were:

- Most had not been to a special event, but those who had rated the event as excellent (9) or good (4).
- It was thought that meetings did cater for both PN and EN, and also catered for children by many, but there were some suggestions regarding the balance.

- Most thought their co-coordinator was accessible and helpful, although many had not tried to contact them.
- 'Online' is read by a clear majority (103) with 'letters from patients' and 'personal stories' being cited as the main wishes for content.

### Some of the many comments (positive and negative) we received were:

- "Although my health prevents me from attending PINNT meetings, please don't think I don't appreciate all your hard work and support. I truly look forward to, and enjoy, your brilliant Online magazine. Many thanks."
- "Don't know whether attending the meeting would be beneficial. Previous experience of being with TPN'ers in conversation tends to become focused on patients' health problems and fears."
- "I am one of these patients who are satisfied with the way PINNT is run. Keep up the good work."
- "I feel isolated due to distance from regional centres - is there a solution?"
- "I feel the Regional Co-coordinators do a great job. A big thank you for all you do."

PINNT is holding its annual Training/Focus Weekend in December where the feedback from the results of this survey will be used to form the basis of a session for our Regional Co-ordinators.



Merry Christmas  
& Happy New Year  
from 'all at PINNT'



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EDITOR: Dawn M Carter

PINNT PO Box 3126,  
Christchurch, Dorset BH23 2XS

Email: PINNT@dial.pipex.com

Carolyn Wheatley 01202 481625  
Justine Bayes 01933 316399

HALF PINNT CONTACTS: Sharon Bell 0141 959 6701  
Sarah Green 01322 383507

www.pinnt.co.uk



# PINNT NEWS

## A word from our new General Secretary



Hello, I'm the new General Secretary for PINNT, having taken over from Dave Schneider at the AGM in July.

I've been a PINNT member since 1998, and last year joined the Executive Committee. You have probably seen my name in Online as the Regional Co-ordinator for the Trent region.

I joined PINNT because, due to Crohn's disease, I could no longer take sufficient oral nutrition to maintain health, and so had a PEG fitted. I was already a member of NACC (National Association for Colitis and Crohn's) and I asked them if they knew of any organisations, which could provide me with information. I received a lovely letter from the then Membership Secretary Norrie McKillop, who welcomed me to the 'select little band'. I found the information sent to me most useful, but more importantly, I knew I wasn't the only one connecting up every night!

By December 2000, I was having trouble with leakage from the PEG site and also actually keeping the feed down, and my consultant told me that I would have to consider parenteral nutrition. What seemed like the end of anything approaching a normal life turned out to be of enormous benefit to me, as on PN, I actually began to be able to live an almost normal life after many years of ill-health.

I attended the PINNT Weekend in July 2002, and the defining moment for me was seeing Carolyn take the AGM with her rucksack on, still infusing; and then disappearing off to disconnect, come back and go on the Bouncy Castle! The whole weekend had such a friendly atmosphere; it made me want to become involved in PINNT. I knew I had skills that I could offer, and the PINNT ethos is very important to me: I will always be grateful for the visit paid to me in hospital by a lady who'd been on PN for about six months – seeing her and how well she was looking and coping made an unbelievable difference to my acceptance of the therapy. I do believe we all have something we can offer each other.

Before I joined the Executive I had no idea of the myriad of things PINNT is involved in, so in the future, I'll keep you up-dated with things that PINNT is doing.

**Justine**



## AND FROM OUR NEW TREASURER ...

Hi, I'm Keith and I have been involved with PINNT on and off for the last 8 years both as a member, Executive Committee member and working for Clinovia with patients in the past.

I am married with 3 kids - all girls aged 7, 5 and 5 months, and a mad dog living in Rickmansworth. I now work for GlaxoSmithKline and enjoy cinema and used to enjoy reading but no longer get the time.

**Keith Nurcombe**

## ONLINE GOES ON LINE ...

Thanks to the new website it is now possible to view Online via the PINNT website. In the future we hope to collate a list of members who do not wish to receive a paper copy but until then you will still receive a copy in the post. If you wish to refer back to a previous edition then this can be done for those published in Spring and Summer 2004.

Feedback regarding our website would be welcomed. Would you like to see anything else on your site ... keep us posted and we will endeavour to make it happen.





## FROM THE CHAIR

Having just returned from the relaunch of our Welsh Regional group it was great to meet familiar faces along with welcoming new people to PINNT. It reinforces why we exist and it is always good to be reminded about the various parameters in which we all survive on artificial nutrition. It was a privilege to meet everyone and I returned home feeling very humble. Letty did a superb job and I feel confident that with the support of local members the group will go from strength to strength.

You seem to like the Restaurant Cards, which is good news. Please keep a record of your experiences and send back your replies in the envelope provided as detailed in the covering letter.

Out of interest – have you had any problems gaining baggage waivers for any form of artificial nutrition fluids? If so please write in and share your story. Things appear to be changing and we would be keen to get a handle on which airlines are performing well.

2004 has been extremely productive for PINNT and we have been slightly more industrious than we expected to at the beginning of our official term of office. Thanks to everyone who has contributed to our continued success.

May I take this opportunity to wish you all a safe and happy Christmas and we look forward to 2005 being a good year for us all.

**Carolyn Wheatley** Chairman PINNT

### PINNT LEAFLETS

ADVICE ON CLAIMING DISABILITY ALLOWANCE AND CLAIMS AND APPEALS

Available free from PINNT to members

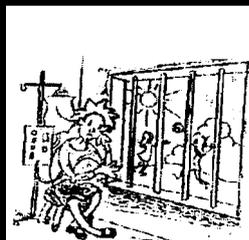
## LITRE Looking into the requirements for equipment

Got something to say about a piece of equipment you use?

Something you could pass on to someone else?

Questions you need answering?

If so contact Geoff Simmonett, 4 Loughland Close, Whetstone, Leicester LE8 4PB or e-mail [Geoffsimmonett@aol.com](mailto:Geoffsimmonett@aol.com)



## HELP WITH DLA FORMS

Many readers will be aware that some people who are on parenteral or enteral nutrition may qualify for Disability Living Allowance and PINNT has produced some guidelines, which give general advice when applying. However, if you suffer from Crohn's or Colitis as well as requiring nutrition support then you may be interested in NACC's guide to DLA which although concerned with Inflammatory Bowel Disease is also suitable for people with other intestinal disorders. Whilst this guide does not contain specific information regarding parenteral or enteral feeding applicants might be helpful. It can be downloaded free from the NACC website by following the Disabilities Benefits link.

## Ports of Call

Some patients for whom it is medically suitable and who wish to be free from obvious feeding signs during the day elect to have a low level feeding device (a port). Reports to date indicate that for some they could not live their lives without it and others say they are problematic. We would like to hear from you if you are fed via a port. Please write in with your personal experiences and hopefully in a later edition we will cover the subject in greater detail.

**WANTED** We desperately need more people to run regional or local groups. We are considering a restructure to ensure we try and meet the needs of all members. If you feel you could spare some time and are keen to help other members then please contact us via any of the numbers shown on the bottom of the front cover.

## SPOT THE BALL

To date the response to the 'Spot the Ball' competition cards has been excellent. Thanks to all who have sold cards and in the next edition we will supply the total raised along with the winner of the returned cards prize draw.



## FROM THE EDITOR

I have to say that I was a little worried when writing this column for the last issue of Online as we'd received no letters from members and I was beginning to question how we would fill the pages! However, much to my relief you've exceeded all expectations and as you can see from this issue we are back to full capacity! So a big thank you to all those who responded to my appeal.

In this issue we have a lively mix of articles, which I hope you find interesting. It was enlightening to read from the feedback on regional groups that 'letters from patients' and 'personal stories' were cited as the main wishes for content of On-Line. So, if you have a personal experience that you'd be happy to share then please let us know.

Finally, I would like to wish all our readers a **Happy Christmas and a healthy New Year.**

**Dawn Carter**

## ARE YOU COMPLETELY OFF YOUR TROLLEY?

In the last issue of Online, LITRE asked for your views regarding the trolley that is issued to HPN patients. **Is it too big? Do you find it easy to clean? Do you think that the split down the middle is a source of bacteria? Have you abandoned yours in favour of something else? Have you any ideas on how the design could be improved?**

We have had several letters with suggestions, but thought we would give you another opportunity to respond with any comments and ideas you may have.

Please give LITRE your opinion by contacting **Geoff Simmonett, 4 Loughland Close, Whetstone, Leicester. LE8 4PB**

E-Mail: [Geoffsimmonett@aol.com](mailto:Geoffsimmonett@aol.com)



## EDITORIAL BOARD



- Dawn Carter • Carolyn Wheatley • Patrick Hastings
- Prof. Gil Hardy • Carola McRae

## AN ODE TO CROHN'S

Oh, dreaded Crohn's disease,  
enough to bring you to your knees,  
the indignity, pain and worry of it all,  
enough to drive you up the wall.  
Op after op, throughout the years,  
enough to drive you to tears.

Through it all we must remain bright,  
maintain our spirits day and night.  
Helping and encouraging others is worthwhile,  
especially when a grimace turns to a smile.  
To wife, family, doctors, nurses who attend every day  
a very big 'thank you' in the best possible way.

Penned by **George Pirie**

## NASOGASTRIC ENTERAL FEEDING TUBE PROBLEMS

In the last edition of Online we gave a warning, which was generated by the Medical and Healthcare products Regulatory Agency (MHRA). **Apparently this is easier said than done. If you have a view on the advice given then please do let us know.**

## Dona&ions



Thank you to all members who have sent donations to PINNT; we are extremely grateful although space does not allow us to mention all of you.

### SPECIAL MENTIONS

£100.00 in memory of Richard Rycraft.

# How to maximize your clinic appointment

**This workshop took place at the PINNT AGM and Symposium during the summer and was facilitated by Justine Bayes and Carolyn Wheatley**

Attendees were given a leaflet prepared by PINNT entitled 'How to Maximise Your Clinic Appointment'. The question was asked: How many make a list before an appointment? A show of hands indicated that about 20% of those who were present do.

There was a discussion about attending clinic appointments: important points were that the patient should always let the clinic know if they can't attend; if you wish to see a specific doctor, it is advisable to ring up before the appointment and check that the doctor will be available.

Some pieces of advice in the leaflet were to think through the likely answer to the question that you ask; for example, if you want to reduce feeding, be prepared if the doctor says no, as there may be reasons connected with your underlying condition which makes this impossible. Another was to take information regarding or the actual drugs with you to the clinic

appointment; attendees were reminded about the form sent out with Online which is specifically for detailing medications. A couple of people said that they felt they should ask more about the medication they take.

It is helpful to supply the hospital with all your contact details, including mobile, so that they have as many ways of reaching you as possible.

There followed a question and answer session, beginning with: Does anyone have an over-caring carer? A 'yes' was indicated by four couples. There was a discussion: for some people it's their way of being involved, some because the patient needs their support to do home therapy and others because they feel they need to know what is happening.

Carolyn read out a note from someone with the reverse problem: how do you get someone to take responsibility for his or her own therapy? The person had tried not going to appointments with them, but felt that then the full facts don't come out at the appointment, and when he came home he didn't report what went on during the appointment.

## **Some comments were:**

- Student doctors dominate, make you feel small and are intimidating.

- There is a technique of power listening to what the doctor is saying.
- You'd drag yourself off a death-bed to hook up, because you know what the consequences are. But you often think about not hooking up and get angry because you must.
- It's a sense of bereavement.
- There is a new system at the Hope, whereby the patient gets a copy of the letters that the consultant sends to the GP.

Much discussion was had in relation to the various ways in which people cope and deal with their care and that of others. At least three people stated that even their close partners didn't do their procedures for them unless in a real emergency, and certainly wouldn't let untrained hospital staff do it. No matter what state they'd always attempt it even though they know the risks; they felt it is better to make your own mistakes than be on the receiving end of other people's.

Justine asked everyone to have a look through the notes and put any comments on it and hand it back in, as it was proposed that this would form the basis of a PINNT publication.

## PINNT – ANYTHING GOES

**This was a general workshop facilitated by Carolyn Wheatley and Keith Nurcombe, PINNT Treasurer.**

Someone commented that they became aware of PINNT because their consultant recommended it; the dietitians didn't push PINNT. Only when she kept asking if there was anyone else in the same position did she find out about us. Questions were raised about how we could raise awareness of our organisation. A suggestion was made to put a poster on the website so that

people can print one off and put it in their local hospital.

Carolyn said that PINNT is conscious of not having the right 'packs'. They are under development but it takes time and money. We supply specific leaflets for specific requests. Posters were sent out to all members and they can request extra from Jackie Huff.

A question was asked about how PINNT raises money – and the answer was from the members. Carolyn stated that

if PINNT had to pay for everything it needed, it couldn't do it; a lot of what PINNT does is funded by goodwill.

Someone suggested that the homecare companies send details about PINNT out; however, as Carolyn said, they cannot send out information, unless the referring hospital authorises them to. Most hospitals are okay about this although some tend to want to make the judgement about when they feel the time is right to find out about PINNT.

## Tubes and Lines

THIS WORKSHOP WAS LED BY **Carolyn Wheatley** and **Sharon Bell**

This session provided a lot of questions for LITRE/BAPEN.

**Question: How long can lines be in for?**

**Answer:** A patient had been told by one hospital that the line was deteriorating and needed replacing; another said to keep it in for as long as possible. It is a Cook Broviac and has been in for 14 years. This issue would be referred to LITRE.

**Question: How many replacement lines can you have?**

**Answer:** One patient has had 19 in 17 years. There are two preferred sites (subclavian and cephalic), which are used, and sometimes it's possible to use the same site again. Lines can be placed through the groin, through the back and in the neck. She said she would refer this to LITRE.

**Question: What about interlink (needle less) connections – should we clamp them?**

**Answer:** To clamp or not to clamp, that is the question! Some patients think that because it's a closed system it's totally safe even if the connector was to become displaced. Someone mentioned wrapping it in gauze and tape, even that won't save the day! A show of hands was asked for how many use a bionector (the most common type of interlink/needle less system): There were 22 with 10 of these using the clamp.

**Comments:**

- It can come loose, it has happened to me, and it can fracture.
- Clamping the line can fracture it.
- If you continually clamp the line in the same place it can fracture.
- Massaging the line helps to ensure that the area where it's clamped doesn't stick.
- Has anybody not been able to get the bionector off in the morning? Yes – it's because it's either tightened up too much or its cross threaded.

It was agreed to ask the manufacturers and LITRE for clamping clarification.

**Question: Should we spray or wipe the bionector and line?**

**Answer:** This was another area to get information from the manufacturers and also gauge opinions from LITRE/BAPEN.

**Question: A patient said she had a jejunostomy, and wondered how often she should change syringes?**

**Answer:** The lady in question stated she is given one syringe a week and was advised to put it in Milton to disinfect it after each use. The hospital reported that as it's not a sterile area, there is no need to worry. However, some hospitals suggest that a new syringe is used each time. This would also be referred to LITRE.

**Question: Even though we are all on PN, why do we all carry out different procedures?**

Carolyn (Chairman of PINNT) commented that she and Dawn (Editor – Online) had watched each other connect to their TPN feed; one took five minutes to connect and the other twenty due to a more complicated routine. Later they were asked to give a talk at the Royal College of Nursing and used this example to ask the nutrition nurses why procedures varied so much. The nurses couldn't answer.

Carolyn and Dawn reported that they had both changed hospitals but had remained with the practice they were familiar with and did not adhere to their new hospital's recommendations. If attending a new hospital, good practice should be that staff ensure the patient is carrying out a safe and effective procedure. Changing to new hospital protocols may cause more harm than good. It's not just about what you do and how you do it, results count – less or no infections demonstrates a good technique. Patients said that the shorter the time to connect/disconnect the better in their opinion.

Under the Scottish Clinical Network there are common protocols, but the patients know that these aren't adhered to across the country. For example, some use gloves, some don't. Even if there were standards it doesn't mean they would be implemented. We should be aiming for minimum standards rather than gold.

# SHAPING THE NATIONAL SERVICE FRAMEWORK (NSF) FOR LONG-TERM CONDITIONS

## 1. INTRODUCTION

The Department of Health announced the NSF for Long-Term Conditions in February 2001. The NSF would focus on the needs of people with specific conditions but it would also cover long-term conditions generally - drawing out some of the common experiences of people who use health and social care services.

The LMCA and the Neurological Alliance were asked to canvas the views of service users, carers, and the voluntary organisations that support them, and to feed these views into the development and design of the NSF. A survey was conducted and focus groups were held between September and December 2003.

## 2. SUMMARY OF KEY FINDINGS

This section outlines the pertinent aspects of the findings, which may assist the Department of Health in identifying areas of particular interest to service users in relation to the development of the new NSF.

### Equal access to health and social care services

- Access to health and social care lacks co-ordination and access problems are often compounded by excessive bureaucracy.
- The introduction of a Key Worker could provide a one-stop-shop for specialist services and speed access to essential services.
- Physical access to the built environment needs to be promoted.

### Independence and quality of life for people who use services

- Access to accessible transport is critical to independent living.

- Rehabilitation services are of particular importance for independent living.
- Increased access to the full range of therapeutic interventions enhances quality of life.

### Choice of services to allow people to live how they want and where they want

- Services must be close to where people live.

### No discrimination

- Discrimination for people with long-term medical conditions is an ever-present fact of life.
- Attitudes and awareness of health and social care professionals constitute the single biggest barrier to access.

### Being included in decisions

- The service-user should be at the centre of the decision-making process not just 'included'.
- Being at the centre of decision-making encourages greater independence and empowerment for the service user.

### Carers should be offered support

- Care support workers employed by local authorities frequently do not offer adequate standards of care for the service user. Low status, low remuneration and low morale were thought to be contributing factors.
- Carers (relatives and family) are not properly valued and lack adequate support. Respite is difficult to access and not sufficient to meet requirements.

### The user of the service should come first

- Service users are often marginalised with care decisions

happening around them, not with them.

- Self-management programmes, where service users are empowered to become experts in their own care, are particularly valued.

### People who find it hard to make decisions should be protected

- Existing legislation designed to protect disabled people should be properly enforced.
- Robust mechanisms for advocacy should be in place.

### Services should be as specialist as people need them to be

- People with long-term conditions should be able to access specialist services according to need and when required.
- Specialist neurological services are particularly difficult to access.
- Health professionals have a poor knowledge base in respect of long-term conditions. Specialists are therefore vital.

### People should be told about choices of financial benefits like Direct Payments and different funds

- People should be informed about the full range of benefits and entitlements.
- A key worker should be identified to support people when they are making benefits applications and determining eligibility.

### People should have high quality information at all stages of using services

- Good quality information should be available from preliminary diagnosis.
- Health and social care professionals also need good quality information to increase their awareness of long-term conditions.

continued overleaf ►

- Voluntary organisations provide valuable peer support and are a rich source of specialist information for people with long-term conditions.

**Other issues emerging from the consultation**

**Community Equipment**

- People want a choice of good quality up-to-date equipment.
- Better quality equipment supplied in a timely manner would save costly interventions in the long term.

**Raising awareness, changing attitudes and training staff**

- Attitudes and awareness of health and social care professionals constitute the biggest barrier to service delivery.
- Work needs to be done to raise the profile of long-term conditions.

- Training in all disability issues and the requirements of disability legislation should be mandatory.

**Communication**

- Many health and social care staff do not understand or accommodate people with communication support needs.
- The range of assistive technology and professional support on offer is very poor.

**NSF Design, Development and Delivery**

- The design and development of the NSF has not been properly inclusive and has excluded key stakeholder groups.
- If there are no targets and no extra funding for this NSF, what are the imperatives for action?
- Too much specificity in this NSF will lessen its impact, reduce the imperatives for action and limit its effectiveness.

- How will this NSF link with other NSFs and existing initiatives?
- The NSF must address ALL long-term conditions.

**Basic Care Standards**

- Basic care standards in acute services are deplorable. People with long-term conditions accessing these services often emerge worse off than they were prior to admission.
- Basic standards of care must be observed and that Essence of Care standards should be reinforced.

**The Role of the Voluntary Sector**

- Voluntary sector providers should be properly recognized and resourced for their vital role in health and social care delivery.
- If voluntary organisations really do have a significant role to play in the NSF implementation there must be adequate funding to enable them to undertake this role.



trent region

We were due to hold our meeting on 31st July at Queens Medical Centre, Nottingham. However, this had to be cancelled due to the very poor response. 41 invitations were sent out; only six replied and just one was an acceptance.

Our next meeting will be in the spring at Queens Medical Centre and hopefully more of the group will be able to attend. It would be helpful and considerate if the invitation could be acknowledged with a reason given if not attending; this will be useful in deciding the way the group is run in future.

**Justine Bayes**

**REGIONAL CO-ORDINATORS:**

**East Anglia**

Jackie Huff 01767 225631

**North West**

Rosemary Martin 0161 998 6201

**Scotland**

Sharon Bell 0141 959 6701

**South East**

Carmel Laverty 01372 275420

**Northern Ireland**

Raymond Toulson 028 9260 4705

**North of England**

John Sturt 0191 565 8651

**Wales**

Letty Johns 01792 521618

**Trent**

Justine Bayes 01933 316399



## Scotland

For our September meeting we travelled to the North again to hold a meeting in Aberdeen. The meeting went very well with members travelling from near and far. It would be great if we could encourage more people from the different areas in Scotland to attend meetings. We were very pleased to welcome 2 members for whom it was their first meeting and I am so glad that we were able to be of some support to them.

We spent time discussing several different issues but all agreed that time spent talking to one another is a good form of support. Sometimes all people need is a word or two with someone who truly understands what they are going through.

Our next meeting will be held in Glasgow and will be our Christmas event, so try and make the effort and come along, our December meetings are always full of surprises.

**Sharon Bell**



## South east region

Our last meeting was held in September in Epsom, Surrey and we had 13 adults and 5 children in attendance.

We welcomed two families who were attending for the first time, who commented that they appreciated that meetings were held outside London as they found it very hard to get round due to needing wheelchair access.

Subjects discussed ranged from the need for standardised care throughout the health care system to waterproof dressings suitable for protecting lines when swimming. One person asked about the availability of a card which could be used when access to a toilet is required and a public convenience is not immediately available. Susanne Wood told us about the CAN'T WAIT CARD. This card is available for people who suffer from Colitis or Crohn's Disease and are members of NACC. However, this card can now be obtained by people who are not members through the website: [www.incontact.org](http://www.incontact.org).

A lively discussion then ensued on the value of peer support within the group and PINNT membership generally. People appreciate being able to talk to like minded people within the setting of the group.

Thanks again must go to Alana for supervising the Half PINNT's table where the children enjoyed cutting, sticking, painting and drawing. A raffle raised £16 for PINNT funds and refreshments were supplied by the in-house caterers.

Our next meeting will be in early March 2005 and we look forward to seeing you there.

**Carmel Laverty**

### STOP PRESS - PINNT RETURNS TO WALES

Letty Johns is now the new co-coordinator for Wales and a full report will appear in the next edition. She can be contacted on **01792 521618** or by email: [dafad@supanet.com](mailto:dafad@supanet.com)



Carol John presenting Carolyn with a cheque following a 10k run.



# PATIENT INVOLVEMENT – HOW AND WHY

**This article is taken from a presentation given by Antje Teubner, Clinical Fellow at the Intestinal Failure Unit at Hope Hospital at the PINNT Annual General Meeting. We would like to take this opportunity to thank her for this contribution.**

A patient is a person with a disease or medical condition presenting him- or herself to health professionals for help. We must not forget, however, that a patient is not only a person affected by illness, he or she is also a person who belongs to a family, a group of friends, or a neighbourhood and will in most cases probably have a career. A patient should be at the centre of medical attention as patients are the ones who have to cope with all the implications the situation requires.

There has been a change within the NHS in the emphasis on how patients are to be involved in their treatment. It is hoped that active patient involvement will lead to good medical practice.

**Successful treatment is always the result of a multidisciplinary approach** – and that most certainly does include the patient!! For a positive outcome the patient must be involved in his or her treatment plan and must have a choice.

**Communication** between professional staff and patient is most important. All involved must know each other's expectations. Goals must be set together and experiences shared. Trust will have to be established.

Health professionals can help by not disempowering the patient. Instead it is important to be responsive and encouraging, and to provide opportunities for communication. Patient and health professionals must be clear about their aims. Patients will have to be included in the planning of their treatment.

Empowering patients means to involve the patient when making decisions. It also means imparting knowledge and information. A well-informed patient will be much more inclined to co-operate. Fluid charts and other aspects of monitoring won't be the same problem, once the patient has understood the need for them, and technical appliances won't be half as daunting, once their functions and workings have been explained. There is every need for health professionals and patients to learn from one another.

**Education and training are important for both, patients and staff.** Existing structures will have to be explained so that they can be understood and trusted. Workshops and focus groups, projects and publicity will all help to raise awareness.

These are the benefits of patient involvement: **while health professionals become more accountable, patients take on more responsibility for themselves.** As confidence grows, there will be room to voice fresh ideas. Safety will increase when everybody understands why something is happening and extra knowledge improves the patient's ability to make informed choices.

Informed consent means involving patients in the development of brochures and questionnaires and by addressing practical issues. **Patients should have access to their own records. It will help to avoid misunderstandings and will provide an opportunity to check and correct.**

Teaching should not only be done by health professionals. Patients also have something to teach: A patient at the beginning and end of a very difficult journey might easily lose sight of the aim. Pain and discomfort are depressing and a patient may not see his or her life come together. Patients may have to accept that things might never be the same again. Medicine and doctors cannot always give the needed assurance and coping strategies will have to be adopted. A fellow patient may be able to give hope to others and to show them how to cope with such problems as body image, dependency on machines, changes in life style and life plans or how to manage going on holiday. Most importantly, he or she can convey that there is life after a prolonged stay in hospital.

A patient, who is involved in his or her care, develops competence in the care of their TPN line or enteral feeding tubes. Patients will become competent in proper hand washing as well as competent in maintaining sterility and the aseptic technique. Or, for other patients, there will be competence in stoma care and other ostomy systems. Eventually **the patient becomes the expert.**



## What can patients do to help?

- Appointments at clinics should be kept.
- If possible patients should involve themselves in research, which will be done in larger centres with a larger patient population.
- If necessary, patients should voice concern and that way help improve situations.
- Patients should make health professionals aware of needs.

All this will also benefit fellow patients.

### Other ways for patients to involve themselves are:

- **PALS** (Patient Advice and Liaison Service), which provide Information, Advice, and Support – your local hospital will be able to advise you of your local PALS officer.
- **PPI** (Patient and Public Involvement Forums). It is part of a wide set of community and healthcare network.
- **NICE** (National Institute for Clinical Excellence). There are patient member guideline groups.



Looking towards the future, there is hope for improved efficiency all round when multidisciplinary teams include patients. Decisions will be shared as all expertise is acknowledged. Relationships within the hospital, the community and throughout the NHS should be good, because communication – the key to it all – is being allowed and fostered.

## NOT ANOTHER BLOOD TEST MUM

**This article is taken from a presentation given by Dr. Maureen Lawson, a Registrar in paediatric gastroenterology at the Northwest Deanery at the PINNT Annual General Meeting. We would like to take this opportunity to thank her for her contribution.**

Having bloods taken is not a favourite pastime for most patients, but especially not for the youngest. No matter how skilled the phlebotomist and how good the veins, there is always the "small sharp scratch", which nobody looks forward to.

### Why then is it so important to have regular blood tests?

Analysis of the blood helps greatly if nutritional support has to be considered. Decisions whether to prescribe Enteral or Parenteral Nutrition will be guided by blood tests. Once nutritional support is

finally in place, the young patient will have to be continually monitored as well. Growth and proper physical development, which will have been delayed by illness and malnutrition in the past, will be regularly checked in order to make sure that the child's body develops correctly.

The Immune System is monitored to see whether it works as well as possible. Mental development and the young person's ability to understand what is happening to her or him must also be observed. For example, is the young patient able to ask questions about the treatment, and can he or she speak about the worries and concerns it causes her or him in their daily lives?

Puberty is a challenging time for all young people, but it is even more so for somebody whose childhood has been overshadowed by serious illness. This may lead to possible social



isolation. Being different at school or in one's peer group makes life hard for a teenager who wants and needs to be part of the pack.

Keeping a young person's blood in the best possible order will contribute to the child's life expectancy. However, this also entails regular blood checks.

Parents and carers will benefit too, if the patient is regularly monitored: often an awkward and difficult youngster can suddenly be understood – and much better supported! – once it has been discovered that there is a problem or that the child simply has not been feeling very well at all.

continued overleaf ►



If nutritional support is indicated, a decision will have to be made whether to opt for Enteral or Parenteral Nutrition Therapy. Also, how long this therapy will likely continue and where it should be administered: at home or in the hospital.

These decisions will have to be taken by a multidisciplinary team, consisting of the patient and his or her parents or carers, doctors and nurses, dietitians, speech and language therapist, psychologist, biochemist and pharmacists.

**This is the pattern of regular monitoring once the nutritional support is in place:**

- growth, i.e. height and weight
- physical and mental development
- bloods: haematology and biochemistry
- radiology: ultrasound and echo, x-rays for the wrist and long bones, MRI

**Haematological monitoring (done at home):**

- |                    |               |
|--------------------|---------------|
| • Full Blood Count | monthly       |
| • Coagulation      | 1 – 3 monthly |

**Biochemical monitoring (done at home):**

- |  |               |
|--|---------------|
| • U & E's , Liver Function Tests, Calcium, Phosphates, Magnesium and Glucose | monthly       |
| • Trigs / Chol.  | 3 monthly     |
| • Zinc & Copper  | 2 – 3 monthly |
| • Vitamins A, D & E  | 3 monthly     |
| • B12, Folate  | 3 monthly     |
| • PTH  | 3 monthly     |
| • Selenium   | 3 monthly     |
| • Ferritin   | 6 monthly     |
| • Manganese  | 6 monthly     |

Monitoring will take place at home, in the hospital and at school and will be carried out by specialist nurses, doctor and by a multidisciplinary team. It will help to adjust the child's treatment according to age and growth and to assess his or her development. Haematology and biochemistry check for abnormalities of the blood. Micronutrients are also monitored for abnormalities. The current treatment will be reassessed: whether there is a need for it to continue, whether it is still acceptable and whether there are advances and new developments which should be considered.

Monitoring – and that unfortunately and inevitably includes the dreaded "small sharp scratch" – ensures the best possible care with as little disruption to life as possible and it ensures appropriate growth and development of the young patient.



## HALF-PINNT

This workshop was led by **Sharon Bell** and **Sarah Green** who were representing Half PINNT.

Sharon stated that Half PINNT is struggling, as they get no feedback from the membership. They reported that the internal Contact directory is not really used; every now and then someone gets in touch and wants to know of someone in a similar condition but this is infrequent. They have tried to involve members with the Schools Booklet, but there has been no feedback from that either. Children really need to know that they're not alone. Without input from families it was felt that there was no way forward.



## WISH I'D FOUND YOU SOONER

I have recently become a member of PINNT and regret that I did not do so as soon as I left hospital in 2002. To hear of other members' difficulties with the Baxter pump giving sets, night time cramps etc. has made me feel much less isolated and 'different'.

I have just enjoyed a short holiday, not far away, in Canterbury, but my first since my condition was diagnosed. I found the holiday booklet invaluable when preparing for it. So thank you PINNT for helping me in various ways to take up a 'normal' life again.

**Ann Dawdon**

**Ed replies:** Welcome to our organisation and hope that you continue to find advice and support.



## STRANGE PHENOMENONS

I was wondering whether anyone else had observed a strange phenomenon. I am on PN, and use Miramed bags with a light protective cover, and a Baxter 6060 pump. I infuse overnight.

I've noticed that when the night-time temperature is warm, there is no PN left at the end of the infusion, and sometimes the bag actually empties completely before the end of the infusion time; whereas in the cooler weather, there is always some feed left in the bag.

Does anyone know the reason for this?

**Justine Bayes**

**Ed replies:** Have any other members experienced this, if so write in and tell us, likewise if any pharmacists can shed any light then please let us know.



## REDUCE, RE-USE AND



I'm an avid recycler and have always been very thrifty having been brought up in the post war period of food and material shortages. Right from the beginning of my TPN feeding I couldn't bring myself to throw away the once used rubber gloves. For the past 4 years I've supplied my two daughters with these for domestic use and gardening as well as using them myself, but it didn't end there!

All the paper such as dressing towels etc can be recycled and I try to throw the minimum amount away. In Hertfordshire we are running out of landfill sites, so perhaps some of the many other patients on artificial nutrition can also do something to help. Some councils can even recycle plastic so check yours out and try and save the environment.

**Phillipa Stower**

**Ed replies:** Thanks for your advice, recycling seems to be important to many of our members.





## HELP AND SUPPORT A PLENTY!

I felt I must write and say thank you for all the information, help and support I have received from PINNT over the last few years.

I became a member in 1996 when I was due to start enteral feeding in an attempt to relieve the symptoms caused by visceral neuropathy, but when this didn't work out I was left in a frustrating state of limbo. The nausea, bloating and stomach pain remained just as debilitating as before, yet I was not considered to be malnourished enough for TPN. The eight years that have followed have been very tough but throughout all this time the one constant source of support I have had has been PINNT.

My quality of life deteriorated dramatically as I struggled to keep some sort of normality in our family life for my children and husband. The first casualty in all this was my job, followed closely by family holidays and any sort of social life. Indeed, my husband joked that sometimes he felt like a one parent family as he faithfully loaded the buckets, spades and suitcases into the car each year and took the kids for a caravan holiday by the seaside. He has also single-handedly undertaken the dozens of days out and social events over the years which have been so important in keeping the thread of normality running through our children's lives.

So there have been some very difficult times and that's where the support of PINNT has been invaluable. When no more medical treatment is available yet the symptoms seem intolerable despair sets in. It has been at times like these when it has meant everything to me to be able to pick up the phone and talk to someone who understands. Sometimes support and empathy can be crucial when further medical treatment is not a possibility. I realise that some members of PINNT may feel that their past painful experiences may be best kept in the past but in fact sharing these experiences can actually help others through very difficult times. It is reasonable to assume that anyone whose health has deteriorated enough to require either enteral or parenteral nutrition will have a difficult and perhaps distressing medical history behind their current treatment, but don't think that sharing your bad experiences will have a negative effect on those you talk to. Knowing that others had been where I was now and had come through it to enjoy a much improved quality of life was very encouraging.

Things are looking up for me and my family now as I may soon be given the opportunity to begin treatment with TPN. I have great hopes for the future. I have been able to read, listen and learn about the pros and cons of TPN and enteral feeding and now feel lucky because I have perhaps had a better chance than most to prepare for this treatment. Eight years is quite some preparation time!

The most important things I have learnt from listening to you all is that all patients are different, everyone copes with their medical condition in their own individual way, and we all have differing expectations from our treatment. I joined PINNT knowing nothing and the only thing I'm sure about after all this time is that I'll only realise how little I still know once I start on the TPN. However, some advice just shines through so after studying at the 'PINNT Academy' for eight years, here's what I've learned.

continued ►



As it's been so long since I've enjoyed a normal social life I know that the temptation will be to rush enthusiastically back to all these activities the moment my central line is in place and the TPN is flowing. However, thanks to the articles I have read and the long chats I have had, I realise that the patients who make the best long term recovery are the ones who take a little time, allowing the treatment to nourish them whilst giving their bodies a chance to slowly re-adjust to the changes that are now expected to take place.

I know I won't need to run a marathon before breakfast in order to judge my treatment to have been a success. For me, success will come in little packages: a day out clothes shopping with my teenage daughter; a game of badminton with my son; an evening at the cinema with my husband; and joining in the family celebrations at Christmas without running out of steam. At the same time I'm totally confident that in time I'll move on to weekends away, followed by enjoying a family holiday for the first time since 1992. But, for now, I'm happy to take it slowly and learn to cope with each stage as it comes, and most reassuring of all, I know that PINNT will be there for me in the future whenever I stumble and need a hand.

TPN will give me my quality of life back, of that I'm sure, but my eight years of waiting have given me benefits others won't have had.

**BB**  
**Derbyshire**

## AN ALTERNATIVE RESPONSE

I am writing in response to a letter printed in the last issue, Allergy to feeding tubes. My son started with a Mic-key button which caused a lot of redness and weeping and we were really beginning to despair at the constant problems with his site, and the continual need for antibiotics which did not agree with him.

That was until we changed it to the "Mini-button". Since changing to this button I can honestly say that it has changed his and our lives, no more leaking or soreness, no more weeping and the need to clean became far less. In fact the less we do to it the happier it is.

We do still have occasional problems with the area but the rough and tumble of boy's play usually cause these. It may not be the answer to everyone's problems but it is an alternative that may ease the difficulties experienced by some with the Mic-key button.

**S Wyer**

**Ed Replies:** Thanks for writing in as it's always helpful to share success stories.





## THE RESTAURANT CARD

After reading the last issue of Online I felt that I must write and congratulate the person responsible for the introduction of the restaurant card. It is a brilliant idea and I hope that the restaurant industry will co-operate.

At the moment I find that it is hit and miss as to whether they will allow you to sit at a table and just have a drink. In some cases this is allowed but you are then charged the full price of the meal. It is not so noticeable if you are with a group of friends but if there are only two of you then it appears to be a problem.

On one occasion my husband and I booked a holiday in Ireland. The hotel was helpful sorting out a fridge for my feed but when we went for dinner on the first night having noticed that it was a set menu I asked if they had any objection to me sitting with my husband and only having soup or ice cream, explaining the reason why. They had no problem with this and so for four nights we had a lovely table and I never felt out of place. However, when we came to pay the bill we found to our amazement that we had been charged the full price of £32 each per meal. When questioned they told me it was because I had used the restaurant facilities, so I had to pay the full price! At the time I was angry and upset but now we can laugh at it being the most expensive bowl of soup ever!

People do not realise that eating is not only a bodily function but it is also a social event. I wonder how many PINNT members find that friends don't seem to ask them out to eat anymore. Having a stoma, I already carry a 'can't wait' card and have never had any problems with staff in shops accepting this. I therefore hope that once I receive my restaurant card I can test it out with the same good results.

**Linda Kuyper**

## AIRLINE TROUBLES

During the past 5 years I have been travelling regularly with KLM to visit my Mother in Germany. I am well known at my local airport in Aberdeen, by the flight crews and even some of the staff at Schiphol airport in Amsterdam recognise me.

Suddenly, quite out of the blue, KLM is refusing to take my usual 25kgs of TPN as medical baggage free of charge and are asking me to pay excess for it. I wonder: have any of you encountered similar problems when travelling by air this year - and how did you get on? Which airline did you fly?

Obviously this is important to me, so please let PINNT know the extent of the problem so that it can be evaluated.

**Carola McRae**

**Ed replies; It is not unusual for airlines to charge for excess baggage even if it is for transporting medical goods, the fee waiver is a concession and not an automatic right, however it does seem rather harsh to suddenly change their policy. Some airlines have always been far more obliging than others, so let us know if you've had problems and also if you've had wonderful treatment from a company. I have to comment here that for the past few years I have been regularly flying with Jet2.com who are fantastic - nothing has been too much trouble with lots of personal attention and even a phone call on my return home to ask for comments so that they could improve their service...top class! Carolyn has asked in this issue for feedback from anyone else experiencing changes or problems in relation to medical baggage problems.**





## OK IT'S NOT FLORIDA – BUT WHERE WERE YOU?

It's Saturday, 31st July and I'd had big plans for today. The chauffeur was booked (my hubby), the limousine was polished (our hatchback) and my 'going out' clothes were ironed (jeans and t shirt).

And the big event? PINNT's regional meeting in Nottingham. So how come I'm sitting at my computer writing this letter instead of enjoying a friendly chat with local members and listening to the talks prepared by the guest speakers? Well, I received a phone call three days ago from Justine Bayes (Trent Regional Co-ordinator) to tell me that today's meeting had to be cancelled because I was the only person attending! I could hardly believe what I was hearing. So come on folks, where were you all?

Having worked hard on our behalf to organise a meeting for us in the Midlands, PINNT then had to cancel all the arrangements, including guest speakers Trish Cargill from the Patient Advice Liaison Service and dietitian Anne Micklewright. I would like to think we're a supportive bunch in the Trent Region so surely we can do better than this! Luckily, PINNT hasn't given up on us yet and is arranging another meeting as I write, so please pull out all the stops and get to the next one if you possibly can.

"But it's the holiday season!" Okay, so I'll concede that Nottingham doesn't quite compare to Florida (although we do have Robin Hood!). Still, there were no news reports of a mass exodus of people from the area today so I guess not everyone is away.

Having said that I do understand that there can be many different reasons why members find it difficult to attend meetings, not least of which are the problems involved with travelling anywhere whilst struggling with less than perfect health. However, if Regional Co-ordinators don't get our support then the local groups will just fizzle out and only the most robust members will be able to travel the longer distances to the next nearest group meeting.

### Barbara Berry

**Ed replies:** Regional groups are endeavouring to move around their regions. Despite this meeting being cancelled it will be re-scheduled and it demonstrates good relations between PINNT and hospitals/centres who support our work.





## YES IT'S GOOD TO TALK.

Yes it's good to talk was a fascinating feature in the last issue that really struck a cord with me. Dr Fortune described many of the emotions that I encountered soon after feeding began which lasted for more months than I care to remember. The final picture and statement sums it all up, it's how you see yourself that really counts.

Now I can distinguish between what I was really struggling with and the things that were really the root of my problems. Apparently I had been unfortunate to encounter a couple of complications soon after my line was put in and I rebelled. I now know this was my anger surfacing but back then I could not recognize this and set about trying to change the world. Why wasn't I told ...? Why didn't you do ...? Why did that happen to me...? – logical questions at the time and the reasons why were clearly explained but I was not happy to accept them, I failed to comprehend that all the text books in the world were not written purely and simply about ME - they had to cover all patients.

With help and guidance I now see that I was **angry**. **Angry** that my life had changed, **angry** that I needed TPN to survive, **angry** that I could not eat and drink as I had previously. Blaming the system for what went wrong was the easiest solution. I recently heard someone say that our failure to accept change causes more problems than we think. I was in denial about the whole situation.

TPN has saved my life, yes it imposes a different way of life now but instead of blaming others for the things that have gone wrong I have already adopted the Dr Fortune example which he referred to as the 'Mental Filter' – do not single out a single negative and apply it to the whole situation. Okay, so to-date my line has been infected on three occasions. Lessons learnt are that I did my best to ensure it did not happen but it did. If I count the days I did not get an infection they far outweigh the days that I did.

Taking responsibility for my feeding in hospital and standing up for my beliefs has also helped. Rather than feeling I need to be accepting of the differing advice I receive, I work on the basis that I need to keep complications to a minimum and keep the counter ticking over to ensure the days since the last complication continue to increase; so now they listen to me!

Finally if you are experiencing problems as described by Dr Fortune – the worst thing you can do is bury your head in the sand. Confront them and seek support, it really is good to talk. PINNT has been a tremendous help as I have realized that it is possibly 'normal' to feel the way I did. The most valuable lesson has been that failing to confront denial is far more restricting than TPN itself. The comments I have heard about TPN being a bind or a problem – it's fundamentally what you make it.

PLEASE keep producing the magazine with such heartfelt experiences. To-date I have not been able to find such honesty via any other source.

**John**

**Ed replies:** Dr Fortune's talk certainly seemed to stimulate much discussion and helped create some understanding of why we feel the way we do. I'm glad to hear that it is already benefiting you.





## BAXTER 6060

With reference to the Baxter 6060 pump, I would like to pass on a useful tip when spiking the bag. One night just after connection, the alarm signaled an 'up line occlusion'. The wretched alarm kept on while I fiddled about checking all the possible connections and the line for kinks. I then restarted the pump several times which had no effect at all. Finally, I turned the spike into a sideways position and the problem was resolved.

I think that when the backpack is placed on the floor, it bends up and can impede the flow. Since then I also ensure the spike is in a sideways position. Oh yes, aren't they difficult to insert? However, I do note that modifications are being made to improve the situation which is good news. Incidentally, has anybody else noticed that the spike goes in more easily with some bags than others? I have 3 different prescriptions – lipid bags are the worst to spike, plain bags the easiest. Extraordinary - I've no idea why. However, I am extremely glad to have the pump which allows me to move around.

**Phillipa Stower**

**Ed replies:** It's another strange phenomenon – just like the one that Justine describes in her letter!



## DON'T LOSE SIGHT OF THE BENEFITS

I have noticed the recent correspondence about the shortcomings of the Baxter 6060 pump and whilst it's reassuring to know they are being addressed, we should not lose sight of the benefits that this pump brings. In my own case, having this pump allowed me to go out in the evening for virtually the first time in ten years. I now go to restaurants, to the theatre or just for a walk – without having to schedule a feed during the day to compensate. I can even move freely about the house without having to sit down next to an electrical socket.

Yes, the backpack is badly designed. We bought a good quality rucksack and adapted it ourselves. This was easier to carry but not the perfect solution since the arrangements for holding the bag were not as good as the original. We have now returned to the Baxter backpack but have adapted it by cutting the stitching in various places to give a greater range of adjustability making it more comfortable to wear.

I also had difficulties spiking the bag at first but observed that Clinovia supplied me (apparently at random) with two different types of feedbag, one being much easier to spike than the other. We asked for all my feeds to be supplied in the easier bag and Clinovia obliged.

A small, low power pump is inevitably less accurate than a big beast made for hospital use. But it is simple to measure how long it takes to empty the bag and thus to calculate the true rate of flow. In the case of my present pump, the true rate is slightly more than 10%. This means that if I am time constrained, I know that I can safely run the pump at an indicated rate up to 10% greater than that which is prescribed.

The things I like about the 6060, apart from its portability, are the long battery life and the air trap (dealing with air in the system was always complex and fraught with difficulty in the past).

**Elizabeth Fraser**

**Ed replies:** Yes, we must never lose sight of the benefits that the pump brings as we all too often focus on the problems. Just one word of caution though, please check with your hospital before running the pump more quickly than prescribed as for some people with specific medical conditions this can be dangerous.





## CAN OTHER MEMBERS SHED ANY LIGHT?

What a great idea the PINNT Restaurant Card is. My appetite is now quite minimal but when I try to explain I only require a small meal, I don't think they believe me - a 6ft 2in, seemingly very fit man, asking to see the children's menu is 'beyond their ken' I'm afraid.

Since losing my small intestine in March 1997 my health continued quite well and I was able to do most things in the gardening/DIY categories. However, in February 2004 my feet swelled up, mainly in the ankles and the upper side of the foot itself. Walking became extremely painful but I did eventually get mobility back with the use of a pair of crutches. The swelling finally improved, following a course of diuretics, and I am now using a walking stick, without too much pain.

During this same period my appetite has dropped from 'healthy' to 'very poor' and I have been plagued

with a considerable amount of nausea. Obviously my practical hobbies have also become nigh on impossible. Some of this may be due to the 'anno domini' syndrome as I am now aged 72 - though I wouldn't consider that excessive. Has any other member incurred similar problems, as generally my Consultant and GP have no magic answer to this problem, in fact they appear quite puzzled by it too?

**Brijan Ing**

**Ed replies:** Thank you to Brijan, Linda all the other members who have written to us in support of the new restaurant card, it would appear that it is being very well received. If you can help Brijan please forward letters to PINNT.



“ Don't forget to look on [pinnt.co.uk](http://pinnt.co.uk) where you can access all kinds of PINNT information, some of which is available to download. ”

## NEXT ISSUE



Please send letters, articles and suggestions for future features to Editor:

Dawn Carter, 8 Lewis Close, Beckton Park, Northallerton, North Yorkshire DL6 3RU.

e-mail: [dawn.carter@tiscali.co.uk](mailto:dawn.carter@tiscali.co.uk)

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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.