



PINNT

Annual Review 2013 - 2014

Adapting to Life on Artificial Nutrition at Home



Back in 1986 when four people had to adjust to life on artificial nutrition at home, they and their families had to cope with the daily practicalities and challenges of these life-saving, complex therapies by themselves.

These same four people decided that no-one should have to go through that on their own again.

Out of that personal commitment, the support group Patients on Intravenous and Naso-gastric Nutrition Therapy (PINNT) was born. Today the charity is simply known as PINNT.

PINNT is a national, independent, not for profit membership charity established for over 25 years providing mutual support and understanding to hundreds of adults and children and their families adapting to life on home artificial nutrition. PINNT provides this support direct via local and regional groups, online via forums and literature and a national telephone and email helpline.

What is artificial nutrition?

Artificial nutrition (AN) is liquid feed that is taken into the body by means of a tube or central venous catheter (CVC). There are different types of liquid feeds and these will be chosen by the patient's nutrition team to ensure each individual receives an intake that suits their body's ability to absorb sufficient nutrients and fluids to sustain their nutrition and hydration status. It is well documented that even people with similar conditions may find themselves on different types of AN.

All types of artificial nutrition and feeding methods will present individuals with a number of hurdles to overcome. Some may have restriction on what they can eat and drink due to their personal medical issues, whilst others may have to adapt to no oral intake at all.

From the experience of their members, PINNT knows only too well how much an oral restriction or no oral intake impacts on the daily lives of the patient and their families. Adjusting to the need to carry medical equipment at all times and to places, to long feeding times attached to a pump – generally up to 12 hours – makes living a 'normal' life a great challenge. This is a particular challenge as food and drink is everywhere, and one of the main social events. Access is easy and it's part of life, a routine way to celebrate, congratulate, commiserate with friends, family and work colleagues. Being unable to eat and drink at such occasions is very challenging. Life on home AN is not normal but is absolutely necessary to sustain life. And if that wasn't enough, it is important to remember that PINNT members will be managing an underlying medical condition as well as their AN.

There are two main feeding types: *enteral* and *parenteral*.

Enteral – where feed is delivered into various parts of the gut to maximise absorption and **Parenteral** – infused directly into the bloodstream.

Further information can be found on the PINNT website: www.pinnt.co.uk/therapies.aspx



To face life successfully and confidently in the community, all of us on home AN need the support of both the medical and nursing professionals and of others also living through the challenges and opportunities of these complex therapies.

PINNT fulfils that second crucial role providing a genuine day to day appreciation of those daily challenges and how they can best be faced and hopefully overcome. PINNT also brings a reality check to the work of health and care professionals who, with the best will in the world, cannot truly appreciate what living on AN is like 24 hours a day, 7 days a week, 365 days a year.

PINNT's aim for 2013/2014 was to raise the profile of the patient's voice. To try and ensure that listening to patients and their carers was actually done and was not purely lip service to pacify people who wanted to contribute to their, or their loved ones, life on home artificial nutrition therapy

Carolyn Wheatley
Chair

PINNT continue to offer complimentary membership for full and associate membership*. PINNT recognise that support should be available to everyone regardless of their financial circumstances. We thank everyone who kindly donates to PINNT so we can continue to offer this. We know how much our members appreciate this.

PINNT's Mission

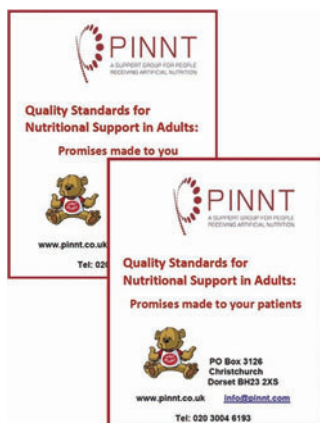
Patients on artificial nutrition want to live the best lives they can – healthcare professionals want to provide the best care they can. By setting goals together **for one person** rather than solely for the management of the treatment and its consequences, the person on artificial nutrition can be supported to optimise their quality of life at home on artificial nutrition. PINNT's mission is to help patients and professionals reach that mutual understanding to the benefit of them both.

PINNT's Aims

- To provide practical information, support and advice for all on home artificial nutrition
- To encourage contact between patients and their families
- To establish a network of local branches across the UK
- To raise funds and receive donations to support and maintain PINNT's services
- To create understanding among healthcare professionals of the impact on the patient of artificial nutrition and its consequences
- To increase public awareness and understanding of home artificial nutrition treatments
- To promote international exchange of views on living on home artificial nutrition

Home Artificial Nutrition (HANs) Awareness Week

Prompted by the declaration from the NHS to put patients at the heart of all it does and the publication by NICE of the Quality Standards for Nutritional Support in Adults in 2012, August 5th – 12th 2013 saw PINNT run its first UK awareness week building on our commitment to improving the daily lives of all adults and children receiving artificial nutrition therapies, improving awareness and understanding of these therapies and strengthening the interaction between patients and health care services.



Two initial new PINNT leaflets were produced which spelt out the promises made in the NICE Quality Standards for patients, highlighting what they should expect and so professionals know what is expected of them. PINNT were delighted when we were asked to modify them for Scotland.

In preparation, PINNT invited seven healthcare professional groups most closely involved with artificial nutrition therapy to respond to the promises made in the NICE Quality Standards and the charity's new leaflet; driving a meaningful partnership.

Responses were received from the British Intestinal Failure Alliance (BIFA), National Nurses Nutrition Group (NNNG), Parenteral and Enteral Nutrition Group (PENG dietitians), British Pharmaceutical Nutrition Group (BPNG), British Society for Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN), British Association of Parenteral and Enteral Nutrition (BAPEN) and BAPEN Medical.

Each day of the awareness week quotes taken from the responses received from the professional organisations were uploaded on to the PINNT website together with two new patient stories. All are available from the home page at www.pinnt.co.uk

Obviously the highlight of the awareness week was to hear from the patients. Each day patient stories were released onto the website, with fourteen in total, each with a reason for their home artificial nutrition and each making a wish which would improve an aspect of their care or homecare service.

A full copy of the stories and supporting statements can be found on www.pinnt.com



Highlights of 2013

Regional Groups: Our expansion to reach more regional communities across England, Scotland, Wales and Ireland continues as PINNT acknowledge the challenges faced by our members when they are travelling long distances because of illness and the demands of their feeding needs. These regional groups help to overcome these challenges, bringing the support, which is so valuable to them, to those who need it.

Networking: Throughout 2013, PINNT continued to strive to support its patients through being an advocate for the needs of those on artificial nutrition by bringing the 'Patient Voice' to those healthcare organisations with whom our members rely on. PINNT vocalise and demonstrate the actual practicalities of life on these life-saving, but also, life-threatening therapies, sharing the experiences of our members and bringing to mind that there is real people involved in every decision they make.

PINNT were invited to attend a number of conferences throughout 2013, including the National Nurses Nutrition Group (NNNG), where we were asked to present a personal experience on life on enteral nutrition, the challenges that are faced along the way and how they are overcome.

PINNT continue to work with homecare companies and industry to highlight the needs of the actual person receiving their therapies; showcasing where issues are arising and working with them to try and minimise these problems. 2013 saw PINNT invited to a number of homecare organisations to highlight the patient perspective of their services and discuss how to improve things.

Facebook: We recognise that people wish to communicate via various types of media and saw a growth of activity on our Facebook page during 2013. We also share and showcase the activities within PINNT. This was particularly active during HANs Awareness week (HANs). Our page continues to encourage general discussion on all things related to artificial nutrition much of which is about the practical aspects of living with these therapies at home. In order to reach as many people as we can, PINNT maintain an open Facebook page, so that it is accessible to everyone. Any private discussion that people wish to have can be held in our member's forum on our website, which is only accessible to our members.

Forum: Acknowledging that some people prefer to discuss things in private, our forum offers a secure place to do this, only accessible to our members (except those who are healthcare affiliates). No questions is considered to be trivial, we know that 'life on line' is challenging and the forum can be a safe place to ask others in similar situations anything that is worrying them.

Videos: Produced in 2012 to support the 25th anniversary, the PINNT videos are still a very popular source of information to patients and healthcare professionals. These short videos cover the most prominent areas of life on artificial nutrition, intended to educate and provide support, hope and reassurance to these embarking on artificial nutrition.

Liz Evans, Chair NNNG said *"watching PINNT videos should be compulsory for ever healthcare professional who cares for people on home artificial nutrition support. Sometimes we need a reminder that there is a person attached to the tube"*.

PINNT hoped these videos would stand the test of time and continue to be a resource for all new patients, as the core principles of managing these treatments at home will remain the same and one year on, we are continuing to use these videos to education others into life on artificial nutrition.

LITRE: LITRE is a sub-committee which runs on an ad-hoc basis in response to products and services. We work closely with manufacturers and suppliers and are proud of the high regard that LITRE is held, being impartial and the voice of the patient. Historically we have looked at a wide range of items that impact on patient's day to day lives. Our LITRE user assessment in relation to ambulatory parenteral nutrition pumps that are available on the market has been a marvellous tool for informing both patients and healthcare professionals as to the options they have when deciding about a high crucial component in relation to parenteral nutrition at home.

During 2013, LITRE assessed an additional pump which was released at the latter end of 2013 LITRE continue

to work with manufacturers to enhance products, adding a few extra touches that will aid patients and their carers, always putting patient safety at the forefront.

The historical use of such pumps was in hospitals, but with the evolution of homecare these treatments are being routinely carried out in the home by patients and their carers' and so different aspects need to be accounted for – LITRE has been able to contribute to positive outcomes for both patients and industry.

The LITRE assessment is recognised by the Department of Health and has become a part of the National Tender for Home Parenteral Nutrition (HPN) Services in England for (adults and children), which states that only ambulatory pumps that have been assessed by LITRE can be supplied by homecare companies at the instruction of the referral unit or centre. The pump is very much a clinical decision and not a corporate decision.



LITRE continues to be the voice of homecare patient specialists.

Patient Groups around the world:

PINNT has some long standing relations with some patient groups and of late has developed closer links with other groups following a shared interest to unite patient groups. Following a meeting between the Polish group, the Oley Foundation and PINNT during the Oley conference 2013 it became apparent that more than one work stream was being considered to bring about a united patient group alliance. Everyone strived to ensure this progressed and it was agreed that the initial think-tank meeting would be scheduled to take place in September 2014. Despite the distances between us we continue to share information and offer reciprocal support networks for

visiting patients and their families. During 2013 PINNT were able to attending the Oley conference. The statement made by Joan Bishop, Executive Director, Oley Foundation last year is as true today as it was then “We welcome members of PINNT at our conferences with open arms. We truly appreciate the amount of effort it takes to travel the distance with HPN in tow”.



Online: We maintain a patient focused quarterly newsletter bursting with patients’ stories and experiences. This is widely circulated and is even distributed to our sister group in New Zealand as well as other members from other groups around the world. Our membership consist of a large number of healthcare professionals keen to hear it from the patient’s perspective; and excellent medium in which we both educate and support.



SHCA: PINNT is a member of the SHCA – Specialised HealthCare Alliance – which has over 80 charity and patient support group members that are involved in specialist health area or rare diseases. The SHCA works hard to ensure that the patient voice is heard by national Government, Department of Health and National Commissioning Board, as well as at regional and local levels with commissions and providers of health and social care. It has kept that clear focus throughout the negotiations around the new arrangements for the NHS. The SHCA keeps its member organisations up to date with developments and provides opportunities to meet with key players in the Government and the NHS.

BAPEN: “It is now well recognised that patients should be at the helm of service improvements and redesign and 2013/14 has seen PINNT at the leading edge of patient centred care and experience based co-design in the field of nutritional care.”

PINNT has continued to play a vital role in all BAPEN's work by providing the patient perspective on how nutritional services, care and treatment can be constantly improved and monitored. During 2013/14 there have been several important programmes of work which have been co-designed by BAPEN and PINNT working together. These include the development of a malnutrition measurement tool, which has seen PINNT advising on the design of the section that measures patient experience and providing expertise during the testing phase of work and the development and design of an integrated care pathway for nutritional care (in collaboration with the Nutrition and Hydration Action Alliance). This pathway aligns well with the NHS England 'Sign up to Safety' campaign, highlighting nutrition as a major safety issue. Through collaborative working, PINNT is a major influence in highlighting the safety issues relating to nutritional care, especially as patients move between care settings.



Another significant achievement for PINNT in 2013/14 was their contribution to BAPEN's Malnutrition Matters Commitment to Act guide; BAPEN's response to the Francis and Berwick reports. PINNT were instrumental in the development of this document, delivering beyond expectations, challenging the status quo and articulating the unique opportunity to identify the top three priorities and responsibilities of patients and their carers in preventing and treating malnutrition.

During 2013, PINNT has worked alongside BAPEN to deliver our strategic plan and meet the priorities of the Association and has continued to join BAPEN clinicians and associated healthcare professionals to represent patients on numerous national committees to improve the design and delivery of nutritional services.

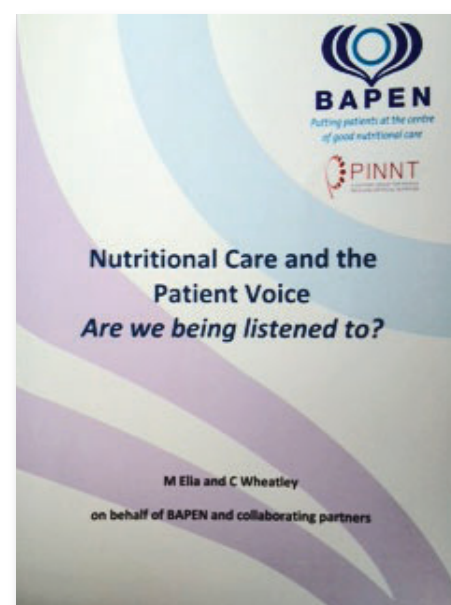
BAPEN sincerely thanks PINNT for its continued major contribution to BAPEN's work. We particularly thank members of the PINNT Executive team who work tirelessly to ensure patients really are at the centre of nutritional care. Together we are creating a new mind-set about the importance of nutrition in the delivery of safe, effective, quality care for all.” Ailsa Brotherton; BAPEN

Patient and Carer Initiative:

PINNT was asked to co-chair a new report concerned with Nutritional care and the patient voice with BAPEN.

It was felt the report was much needed given the lack of work into whether the patient perspective was being taken into account in regards to nutritional care and despite many things being actively addressed, a number of questions about patient and carer perspectives remain unanswered. This report specifically aims to address those questions; has there been a substantial improvement across patient care in England over the years? Have the strategies outlined in many previous reports been effectively implemented with favourable outcomes for patients and carers and has the recent reorganisation of the NHS resulted in greater clarity and improvements in healthcare, or has there been deterioration?

PINNT, like those in the report firmly believe that more needs to be done to improve management of patient with nutrition and hydration problems and if the messages derived from the report can be heeded, then the nutritional care of patients can be improved and those who took part are ready and willing to be actively involved in making this a reality.



Donations

Vygon – Study Days for PINNT

£2856. 2006-2013 exceeds £27,000 – From our earliest encounters, Vygon were always impressed with the enthusiasm, focus and drive of the representatives of PINNT. The level of support offered to members, and non-members, is always evolving to ensure that patients are given up to date advice and guidance that might not be readily available from clinicians. The willingness to engage and work with industry, offering a practical perspective gained from personal experiences has enabled quicker and better development of products and services for patients and carers.

Without PINNT there would be a huge gap in the support of many patients receiving artificial nutrition and Vygon are proud to be able to support such an important charity.

Graham Milward

Technical Support & Product Realisation Manager



NPS Pharma

£5000 – Aware of the dedication and commitment to support people on artificial nutrition at home, NPS Pharma kindly donated £5000 to be utilised by PINNT for media to enable the continuation of PINNT awareness raising efforts.



BUPA Westminster Mile – inaugural race

PINNT were delighted to receive complimentary places in the inaugural Bupa Westminster Mile, 26th May 2013, raising not only cash but also, and most importantly, awareness of PINNT and the support it provides.

Thousands of runners, supporters and visitors were drawn to Buckingham Palace and St James' Park for the Olympic Legacy event run by the London Marathon team and sponsored by BUPA. The route for the mile run started down The Mall, round St James' Park, passing Horse Guards Parade and the Churchill War Rooms, before turning into Birdcage Walk with Wellington Barracks to the left, before turning into the road right in front of Buckingham Palace. Team PINNT, plus their families and friends, gathered in Green Park, prior to the race. Everyone had pledged to finish within 15 minutes!

As each member of team PINNT crossed the finishing line emotions ran high. For some it meant that little bit one. Samantha de la Querra "I came in last but feel very proud to have completed the mile. I only came out of hospital recently so it was a real challenge, but it was great to be outside doing something active for a change."

Another runner, Tammy Huff, ran a great race in memory of her mother Jackie who gave so much to PINNT, and finished in a great time. She said after the race: "It was emotional. Out of all the running I have done before it was the shortest distance physically but the longest emotionally."

Jasmine Cheesman, mother of 3 year old Isobel who was on artificial nutrition, ran with a fully packed 'see through' backpack to demonstrate the kit that adults have to manage on a daily basis. Jasmine, from Hedge End and co-organiser of the new PINNT Southampton group, said after the race: "Really brilliant, it was a great atmosphere. Running with the backpack was a challenge. It was heavy but do-able and really brought the message home about what it's like for people who rely on TPN on a daily basis."

All of our team finished within the 15 minutes allowed and were proud to have run for PINNT.

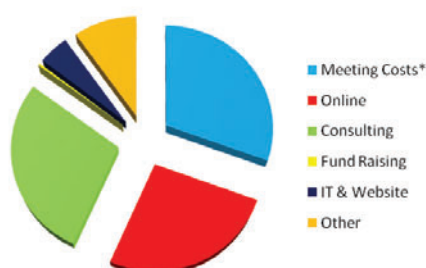
The whole experience was so momentous on so many levels, with genuine people doing something personal for PINNT. The relationship between PINNT and BUPA proved to be as strong as ever and Industry supported PINNT too with the donation of the rucksack and equipment from Inspiration Healthcare and Micrel. We may not have had lots of runners and the biggest team but PINNT truly believe that the biggest winners on the day were PINNT as we demonstrated how we can interact on every level. This will hopefully become an annual event for PINNT.

Everyone's commitment and story counts!



Statement of financial activities

Payments:



Receipts:



*these costs include all Trustee meetings, sub committees and regional/local group meetings where charges apply. Travel, refreshments, accommodation and other costs incurred are included here. All expenses related to trips abroad are possible due to separate sponsorship. No money from PINNT funds are used.

Quotes

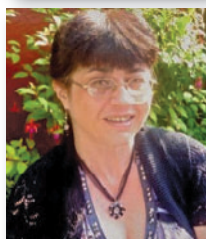


Adam "Finding PINNT was the best thing that I ever did in relation to my treatment. Gaining the confidence to travel and see my treatment as a positive part of my life has enabled me to move forward in a positive way. I enjoyed being part of the PINNT videos. Being able to share my experiences will hopefully inspire others as PINNT members before inspired me. I was part of HANs week 2013 and hope that my contribution enables PINNT to further the work they do. Even though I grow in confidence there are times when talking to PINNT is invaluable".

Tracy "Hosting a regional group for PINNT allows me to give something back to PINNT in return for all the support I received when I started life on home artificial feeding. Offering words of comfort and support to fellow members is gratifying. Everyone feels part of a family knowing we can turn to each other in times of need or on a day to day basis. Each meeting welcomes new people and as we progress we will retain our open door policy. I have now also committed to offering time to sit on the EC within PINNT to try and help support the role of the patient voice being heard externally. I know how important PINNT was to me in those early days, always will be, but I want to get out there to ensure people know the true worth of PINNT"



Sylvia "As a retired nutrition nurse I spent a number of years viewing home artificial nutrition from the healthcare professional's perspective. Having never lost sight of the patients' needs, I am now able to offer more time ensuring a supportive network is available for their benefit. Many patients find huge support from talking to other people in similar situations. The exchange of ideas provides valuable help in accepting and adapting to the need for home artificial nutrition. I have the role to help support and set up new groups around the country which is a joy to do when people come along and realise they are now alone. Social media is not for everyone and the face to face meetings still carry a lot of worth".



Kath "PINNT provides common sense information that people need to navigate through the system. It is also a very useful source of peer support"



Tara "PINNT really helps us to feel less isolated and helps to share idea about living with artificial feeding"

Molly "It was wonderful to find and join PINNT. I had felt very alone and it was so good to speak to others in a similar situation and to get advice and support"



Plans and events for 2014

We will continue to support and be hosting regional and local meetings. PINNT support network is continuing to grow, but more importantly is that we are moving towards it being closer to the people who need it.

We will continue to network with other support groups around the world by moving forward with the International Patient Group, which will include groups from around Europe, America, Australia and New Zealand.

We will continue our work raising awareness of home artificial nutrition through another awareness week in August 2014, expanding on the work done in 2013. We intend to seek support from homecare industry and key healthcare professionals organisation to ensure patients are being put at the heart of their decision making. We will build on networking with as many professional groups and companies to ensure the patients are not only seen but heard.

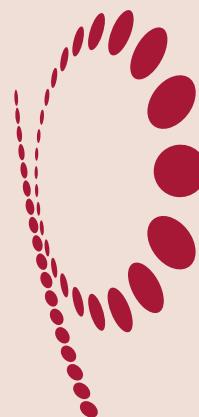
Benefits of membership

Not only does membership to PINNT offer support on a personal level, but it offers a wide range of dedicated supportive literature. Four quarterly newsletters, Holiday Guidelines, literature in relation to considering travel and travel insurance, a free restaurant card (a visual communication to explain the inability or limited oral intake), access to meetings and the members' private forum, plus so much more. Our member's benefits evolve in response to the members' request. We go the extra mile to deliver on information or support they need.

Donations - how we use them

We receive two types of donations; 'time' and 'money'. Monetary donations enable us to fulfil our aims and objectives and meet the needs of our members. We are extremely fortunate to receive regular donations from members and one off donations from companies and individuals. Due to the current climate fewer people have spare money to donate to good causes. Usually the larger charities which hit the headline are worthy, of course they are but so is PINNT. Our work relies on good will from our team of volunteers.

Partnership working – PINNT welcomes enquiries from other support organisations, potential sponsors and Trusts, to explore how we can work together to improve the lives of those people dependent on home artificial nutrition. We recognise the boundaries this may cross in both care setting and disease statuses. Good nutrition and hydration have a major impact on all outcomes; PINNT strives to make life easier to manage on home artificial nutrition.



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