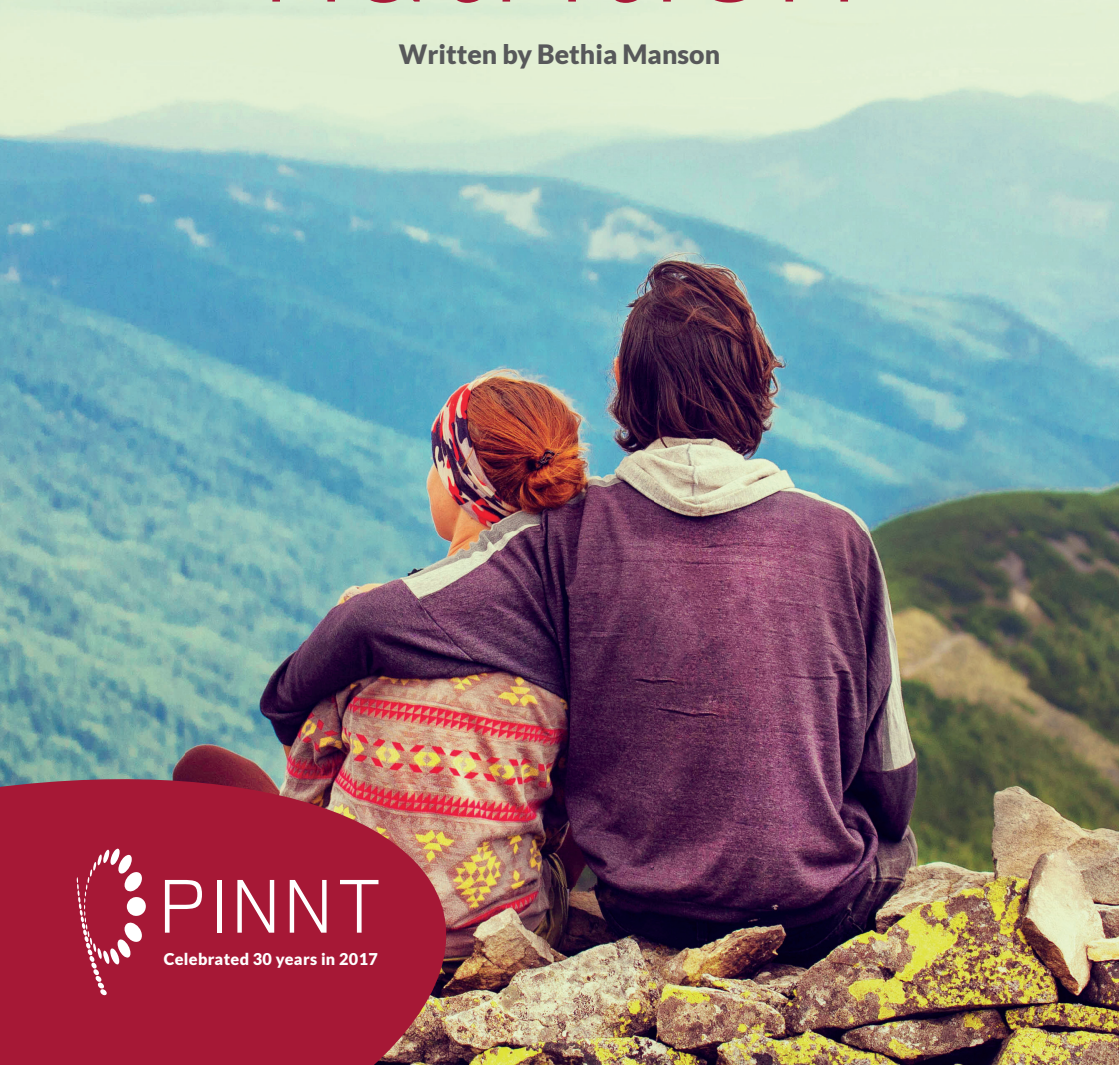


Living with artificial nutrition

Written by Bethia Manson



PINNT

Celebrated 30 years in 2017

Forward

Life on artificial nutrition is an unusual life. It could be construed that this is a life that was not meant to be. After all artificial nutrition is a form of life support. It is not something that is known about. It isn't on the science or biology syllabus at school, there are no programs on it on the television and no one talks about it. So when someone needs to have it for medical reasons, they can have lots of questions or make lots of assumptions. Medical teams know about hospital artificial nutrition, especially when it involves the gut (enteral nutrition) and to a lesser extent when the nutrition is directly into the veins (parenteral nutrition).

However, when it comes to having parenteral nutrition at home this is a specialist area and most healthcare professionals are much less knowledgeable. This creates a conflict for patients who look to the medical and paramedical professions for guidance and often they get variable answers.



When it comes to answering difficult questions like socialising, relationships and sex, most patients find it hard to ask their healthcare professionals, and in return most healthcare professionals find it hard to answer. It is often taboo and it shouldn't be.

Just occasionally in life someone special appears. Bethia Manson is very special. Her drive for life and enthusiasm is infectious. Her ability to get through medical school while dealing with her intestinal failure and managing her intravenous nutrition is quite remarkable. Now she wants to help others and has the ability to do this by reaching out to other patients and giving guidance on the issues that are taboo. Through her words and images, she will help to start conversations and help others to develop confidence. This is a gift. I hope that this helps many other patients with a difficult and sometimes devastating condition, but with support these patients can be shown that it is possible to rebuild their lives and live it in the way they want to.

Dr Simon Gabe

*Consultant in Gastroenterology
& Intestinal Rehabilitation*

*Chair of the Lennard
Jones Intestinal Failure Unit*

St Mark's Hospital, Harrow, London

Introduction

The impact of illness is never confined to the part of the body that is physically affected. It can be global and include the effect on your family and loved ones.

Whatever the journey that has led you to require artificial nutrition, you and your loved ones will have faced many physical and emotional challenges along the way.

The primary aim of this leaflet is to provide a platform for you to acknowledge, think about, and if you choose to do so, discuss:

- **Your story so far**
- **Your successes**
- **Any current worries or concerns**
- **Future goals and working towards achieving them**



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The emotional impact of artificial nutrition:

Whatever your story, there is no doubt that you will have been on a roller coaster with limited control over your journey.

For many people artificial nutrition will hold two titles:

- Viewed as the last resort that they may have gone above and beyond trying to avoid
- A lifeline; something to sustain them and enable them to move forward with their lives

It is therefore unsurprising that for most people artificial nutrition may have both very positive and very negative connotations. Holding these opposing positions together can be challenging, leading to difficulties in coping and managing your ongoing condition.

This mixture of joy, relief, desperation and worry makes for a very confusing melting pot, and because of this it may be difficult for you to make sense of your feelings. It is absolutely normal to experience both highs and lows.



“

Once I started PN I put on weight, and my mental health improved.

(27 yr old (F) Gastroparesis. Infuses for 20hrs 4 × Wk)

“

Parenteral nutrition for me is my saviour, and I hold it in high regard as such... it was only later, once my future seemed more stable that I started to worry about the finer intricacies of being dependent on something so precarious.

(25 yr old (F) PN 7 nights/Wk)



The best laid plans....

When you visualised how your life would be, undoubtedly being dependent on artificial nutrition was never in your grand plan. Although it cannot be described as the ideal situation, such a huge change in your life does provide you with a unique chance to reflect, and benefit from the joys that a new perspective can bring. Often people speak about growth through adversity, and this can be seen in many people's stories within this booklet.

Whatever you have been through, good or bad, your experiences have played a part in forming the person that you are today, and they should never be trivialised.

“

I am getting a zest for life back. Learning to accept my illness. Learning to love myself again. Just because I have a debilitating illness it doesn't mean that my life needs to stop. We just have to learn how to adjust to our circumstances.

(27 yr old (F) Gastroparesis,
PN 4 days/Wk)

“

Every now and then I dream that my line has broken, or that I have forgotten how to connect my PN safely, and I wake up in a panic.

(25 yr old (F) PN 7 nights/Wk)

The impact on psychological well-being:

For many people the events that have led to the need for artificial nutrition will have been very distressing. After such events it is common to experience heightened emotions, and in some cases flash backs to the event itself. Sometimes this can be an example of trauma or Post Traumatic Stress Disorder (PTSD). “This can be particularly difficult and frightening, but please do not be alarmed by this. There is help available from mental health professionals which can improve these symptoms, and talking about your experiences and feelings, rather than bottling them up, can really help”. - Dr Joanne Ablett (Consultant Clinical Psychologist)

It is well known, and in no way surprising, that people living with chronic (long term) illness are more likely to suffer with low mood, depression, and/or anxiety. Time in hospital or being very unwell can reduce a person's self-esteem and self-confidence which can sometimes lead to anxiety and low mood.

Quality of life is often talked about in relation to managing a chronic health condition. Artificial nutrition sometimes presents restrictions and barriers to doing some of the things that you want to do, impacting on the quality of your life.

It is helpful to think about your goals and the extra steps that you need to take to achieve these in light of any limitations that you may be facing. You might find it helpful to talk your goals through with someone, whether that be a healthcare professional, friend or family member. Try to speak with someone who will help to motivate you to achieve your goals, rather than be overprotective and hold you back.

Although it can be extremely difficult to begin to process all that has happened that has led you to artificial nutrition, taking stock of where you are now, today, can be the catalyst that helps you to move forward. Your journey on artificial nutrition is a new beginning, and the start of a different, but bright future.

“

When your child is well it is important to step back, and leave them to get on with their life, but also to always be there when they need you.

(Mother of lady on PN since a baby)



What could help?

Whether you are feeling on top of the world, or fearful and anxious about something it is important to have an outlet of some kind.

Some people find sharing their thoughts with others helpful. Discussing concerns with friends or family where appropriate can provide great benefit; alternatively, you may find it useful to have confidential conversations with a health professional.

Other people are innately private and find verbalising their concerns very difficult. If this is true of you, this is not a reason to face your worries alone. Something as simple as writing your thoughts down can help to put them into perspective. Writing thoughts down can also provide an easier means to benefiting from sharing your concerns whilst bypassing difficult face to face conversations. You may like to write your personal story, and if you feel comfortable, share it with others. This way, your struggles may help someone else in a similar situation in the future, at the same time as helping you to make sense of your own experiences.

- **Keep a diary to help reflect on your feelings**
- **Talk to someone you trust**

Research has shown that having a conscious awareness of the way that we feel can reduce anxiety and depression. This means that taking the time to be aware of your emotions and learning to take stock of what you are feeling (although sometimes uncomfortable) is important. Writing a diary or practising meditation or relaxation can help us to stay in touch with what is happening to us in the here and now.

The future is yours for the taking

Setting goals, starting with small steps can be really helpful in motivating us, especially when you have had a setback. Write some goals for the next week, the next month and the next 3 months. If you find yourself thinking further ahead, add notes for 6 and 12 months but 'shelf' those items until you achieve your first goals. This prevents you from becoming overwhelmed with the end goal and helps you to focus on the steps that you can control to reach them. This may include getting fitter if you have been unwell for a long time, or doing some vocational training/an activity you want to try. Anything which is meaningful to you.

It is also helpful to think about your 'values.' Values are not goals, but rather ways of living. They reflect the type of person we want to be, rather than being about individual achievements. For example, if you have had to give up a particular career, you can still examine the value which led to you wanting to do that career and then look at other ways you can still live by this value and plan some committed action to help you with this. This way of exploring life may help you to come to terms with some of the limitations that you now face, whilst you pursue activities that you enjoy.

– Dr Joanne Ablett (Consultant clinical psychologist)



“

Some things require more planning than they used to, but when I get there the experience is even sweeter for it.

(25 (F) PN 7 nights/Wk)

“

I don't allow artificial nutrition to hold me back from doing anything.

(26 yr old (F), PN 7 nights/Wk)

Food for thought

If you require artificial nutrition one of your most basic human needs has been redefined.

Such a massive adjustment to an intrinsic behaviour will no doubt be difficult.

There are many different reasons why artificial nutrition is needed, and because of this, everyone's relationship with food and drink will be different.

Some people will have to be more careful about what they eat and drink, and the timing of their meals, whilst others will be unable to have any oral intake at all.

“
No longer is the simple,
almost unconscious,
act of eating and drinking
part of your life

(63yr old (F) PN 7 nights a Wk)



You are unique

...and because of this, this section will touch on some situations that you may encounter, and also discuss some that may not be relevant to you.

Very limited/ no oral intake:

If you are unable to eat or drink you may feel as if you are being tested in more ways than one; coming to terms with the unimaginably difficult situation of not being able to eat or drink yourself, whilst at the same time watching those around you continue to indulge as normal.

Socialising:

As food and drink are often a major part of socialising, it is important that your inability to eat or drink does not act as a barrier to you taking part.

Social situations may seem daunting for people on artificial nutrition, with worries that you will be asked questions that make you feel uncomfortable, or that people may treat you differently if you are not partaking in a meal.

Restaurant card

Free for all tube fed patients and TPN/HPN patients
PINNT members: nibbling, socialising & sharing make for happy HAN people.



Some situations may be easier to manage than others such as a simple “no thank you” at a drinks party.

Where a social situation is centred around a meal it can feel more difficult, and some people find that they would rather not attend an event than have to give an explanation for why they are not partaking in the meal.

It takes confidence to give a full explanation of why you cannot eat or drink, and in some situations may mean revealing information that you wouldn't necessarily want to share.

It may be helpful to have a pre-planned answer for these situations. This would enable you to share the information that you are comfortable with, without stumbling over your words or saying something that you may later worry about.

“

I'm 21, soon 22 my friends drink and have tattoos or drive cars- I only drink water and I'm hooked up to PN most of the time- I get tired easily - sometimes I wish I could go to the pub and party, I think people can't understand why I can't have alcohol

(21 yr old (M) PN every day and night)

“

So much of our social life revolves around food, “Ladies that lunch”, “meet me for coffee”, etc. Food is a social pleasure, a sensual experience, an exploration of different cultures and ways of life. As a cook, you spend time planning, preparing and presenting food, it's an expression of love and a demonstration of your skills... Take all that away, and you are left with a void.

(63yr old (F) PN 7 nights/Wk)

Another approach would be to have something like a PINNT restaurant card in your wallet; a simple card with a minimal explanation of why you won't be eating/drinking, that you can show to a waiter, or to the host of the meal. The PINNT restaurant card provides a subtler way of getting your message across without having to draw more attention to yourself than you may like. Using a simple written message such as this may also be useful at work gatherings, or meetings where you do not feel that a fuller explanation would be appropriate.

Food with friends and family:

- How do you balance your own needs and desires when it comes to food and drink with those of the people around you?
- It is of course true that not being able to eat or drink has a profound impact on your life, but unavoidably those around you will be feeling the impact of your requirements too.
- Unfortunately, as with everything to do with artificial nutrition, there is no one size fits all answer to get around this problem.
- Don't let food be the elephant in the room...
- Find a way to be involved with the social aspect of food; for example, meal preparation



It is common for family and friends to feel guilty about eating in front of you, knowing that you cannot join in. For some people, this in turn leads to feelings that you are preventing family and friends from going about their normal routine and enjoying their meal.

Although this is a difficult situation, talking openly together could help. It may be useful to each explain the things that make you feel comfortable and uncomfortable around food. Once you have been able to understand one another's concerns it might be possible to find a compromise that you are both happy with.

Some people find that getting involved in meal preparation makes them feel less isolated at mealtimes and can also make their family/friends feel more at ease.

“

I have one tip: Buy a good quality Thermos flask. When you go for coffee, ask for it to be put into the Thermos. This way it will stay hot all day, you don't then have to leave behind what you can't finish. It's very "on-trend" to use your own cup at the moment.

(63 yr old (F) PN 7 nights/Wk)



“

I can drink small amounts and count my lucky stars that I can.

Being around close family and friends who understand this is usually absolutely fine. But, it can be really awkward being at a large gathering and not eating when everyone else is. I'm not usually bothered personally, but I find it does make everyone else deeply anxious if one guest is excluded.

I'm still learning how to tackle this, but so far, I've found that to avoid this, I now order something, occasionally the same as everyone else (a small version if possible) and move it around the plate, taking a couple of small bites depending on how I'm feeling. If I'm with family and friends who understand the situation, they'll often dip in and help me out, making it look like I've eaten. It's harder for me, but much easier for everyone else, and having less fuss generally makes my life easier and means I can enjoy the day more. From experience though, ordering a small bowl of soup stops any questions dead, and usually isn't too expensive either!

(Lady on PN and EN alternate days)

“

As for the psychological aspects of not being able to eat, it's often the urge to chew which eventually gets me.

I've tried chewing and spitting (in private, although with a bit of practice it is possible to do this very discretely) but for me it just isn't the same, and there are occasions and foods that almost justify the inevitable payback (sickness and pain).

Sitting at a dining table when everyone else is tucking into a Christmas roast, or steaming puddings, can be really difficult, and at times like this I think myself fortunate that I'm able to have a small "taste".

For the rest of the meal, it can help to have something to "do" to keep the hands busy while everyone else is eating. This might be the washing up, but you risk missing out on the conversation and bonding that happens over the meal, and frankly, you're not making the mess so why should you be the one clearing it up?

A good friend always has some knitting to hand and sits and knits while others are eating which is both sociable and useful, as well as a good conversation starter meaning that you're included in the discussion from the start!

(Lady on PN and EN alternate days)

If you eat/drink:

If you can eat and drink you may have had to make some changes, such as the types of foods that you eat, and the timing of when you eat and drink.

Depending on your reason for needing artificial nutrition there may now be some foods that you have to avoid, and some that you will have to eat in smaller quantities.

When eating out, or at a friend's house you may be asked why you are not eating certain foods. Although being put on the spot can be upsetting, it is important to remember that the amount of information that you share is your choice, and that often people can be placated with a very simple answer such as "I have a medical condition that limits what I can eat". Never share information about your medical condition just because somebody else is trying to satisfy their curiosity and putting you under pressure to do so.

It is also important that you have the courage to say no to people. Never give in to eating or drinking anything that you think may harm your health to satisfy others. Your health is your number one priority, and you should never let embarrassment or persistence from others sway you from looking after yourself in the way that you know you must.



Plan your food around your day:

People who suffer from vomiting or diarrhoea after food or drink, or those with stomas may benefit from planning the types of foods that they eat to fit in with their daily activities.

An example of this would be: on a day that you are going to work, have a trip planned or know that you will need to make a long journey, you may have to tailor your diet to minimise the need for toilet breaks.

Making small changes such as having toast for breakfast instead of cereal, or bigger changes such as not drinking throughout the day until you are back home and avoiding foods with a high liquid or fibre content during the day, may minimise the worry of finding a toilet quickly; making your day run more smoothly.



Conquering the thirst:

Often the most difficult change for people on artificial nutrition (especially those with high volume losses) is managing how much fluid that they drink.

Thirst can become all encompassing, and it can feel like an impossible challenge not to drink when your instincts are telling you that you need water.

It is important to understand that the thirst that you feel is directly linked to the amount that you drink. The more that you drink, the higher your losses will be, and the thirstier that you will become.

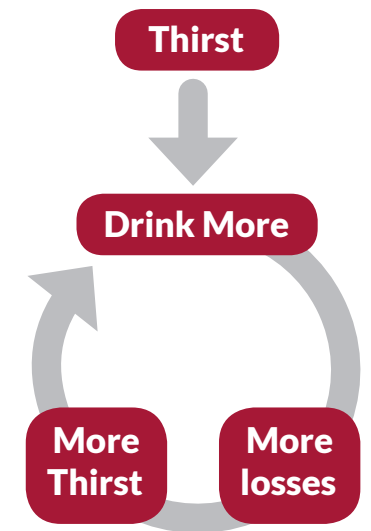
As you can see this can turn into a vicious cycle.

Paradoxically the only way to overcome the thirst that you feel is to limit what you drink.

Speak to your Gastroenterologist, dietitian or nutrition team about how much you should be drinking in a day, and then really try to take control of your own thirst but sticking strictly to your limit.

It may feel difficult at first, but once you have your fluid intake under control you should feel much less thirsty, and the challenge of drinking less will become easier.

Splash cold water on your face and neck to cool down on a hot day. Or carry a cooling water spray with you.



Impact on family & friends

As a family member or friend of someone on artificial nutrition it is likely that you will have seen them go through an awful lot, perhaps over a long period of time.

Watching a loved one suffer, and the feeling of helplessness that often accompanies this is likely one of the most difficult things that you will have ever experienced.

Due to the complex nature of some of the problems that lead to the need for artificial nutrition, at times you may have had the extra stress of acting as an advocate for your family member or friend. Add to this the other pressures of life; work, finances, juggling family and social responsibilities, and things can quickly become overwhelming.

“

As a parent some things are heart-breaking: Seeing people point and stare, never being invited to houses or parties, a kiss on the cheek in an anaesthetic count down, hours in surgery just waiting to hear if all's ok and knowing a cuddle can't solve everything....

(Mother of young man on PN since a child)



With so much of your energy and worry focussed on the person who is unwell, it is very easy to overlook your own well-being.

When the person who was unwell was undergoing their recovery period, you are unlikely to have had a chance to recover yourself before you were expected to carry on as normal.

Although the illness did not happen to you directly, the impact that it will have had on your life is by no means any less significant or important than the impact it has had on the life of your family member/friend.

Both your physical and mental health will have been under strain whilst your loved one was unwell. It is extremely important that you make time to look after yourself. Do not be afraid to ask for help from friends, family or health care professionals.

Prioritising your own health will be one of the most important things that you can do to aid your own recovery, as well as aiding the recovery of your loved one.

“

I have had to be the voice for my daughter when she has been too unwell to voice her own concerns.

(Mother of patient on PN since a baby)

Understand the importance of looking after your-self

“

Children are amazing and just accept whatever they have to cope with. Not being able to eat, having many surgeries and spending half your childhood in hospital just becomes the norm. Using drip stands as a skateboard and whizzing around the ward and announcing their goal in life to be able to fart!

It's really important to be positive and make the most of life, you can't get the time back. Like any other family it's making memories and having quality time together that's important. Yes, it's hard, and an emotional roller coaster, but you can have good times, it might just be different from other peoples, for instance going anywhere takes a lot of planning and you certainly don't travel light!

But it's all worth it, so I would say to anyone who's a parent or carer of a 'TPNer' get those special memories made.

(Mother of Young man, on TPN since a child)

Relationships

Dating:

Dating takes a lot of courage, no matter who you are, but when you add in the extra complication of being on artificial nutrition, it can be an extremely daunting prospect.

As well as the normal pressures of trying to make a good impression, and working out whether the person ticks your boxes, there is an extra layer of butterflies for you to contend with.



Internet dating:

Some people will be torn over how much personal health information they want to share on their internet profiles; worried that not sharing any information is dishonest and could cause problems further down the line, yet also concerned that sharing health information may sway people before they have the chance to get to know you. Striking a balance between providing an honest depiction of yourself, at the same time as getting across the defining aspects of your personality can be very difficult when internet dating.

Some people will want to mention their health and artificial nutrition from the off, whereas others want to get to know someone before going into the details of their health.

Both of these approaches have pros & cons.



Including artificial nutrition on your profile:

Pros: Spelling it out from the start may help negate the question of how to start that potentially difficult conversation further down the line.

Cons: Many people will never have heard of artificial nutrition and may conjure up incorrect preconceptions of you based on the snap shot of information that you provide. Because of this, this approach may act as a barrier to you being able to make first contact with people; stopping you from having the chance to show off your personality.

Not including artificial nutrition on your profile:

Pros: Holding your health information back can make the beginnings of internet dating easier, as it will put you on an “even keel” with everyone else, giving you the opportunity to talk about other aspects of your life, and bond over common ground, before broaching the subject.

Cons: If you don't put anything about your health on your dating profile you may feel as if you are with-holding information, and therefore starting off on the wrong foot. You may also worry that avoiding the topic will make it more difficult to introduce it further down the line.

“

My girlfriend told me about her PN and stoma on our second date... didn't see that one coming! It would be a lie to say that I didn't initially question continuing our relationship, however I quickly realised that none of what she had said detracted from how awesome she was. Over time we talked about PN and stomas, and how they would impact our relationship; life expectancy, pregnancy, socialising, sports, life goals and of course sex. It took me the best part of a year to comprehend the emotions and feelings associated with being in my first relationship, and the impact of PN was an integral factor to consider. My advice? Allow time and be open.

(24yr old man)

You are so much more than your medical condition; Let people know who you really are



Whatever you decide to do, please remember:

Unfortunately not everyone on internet dating sites are polite, and there will always be people who will pick on things that they do not understand.

Being mindful of how much personal health information you reveal may help to protect you from experiencing such hurt.

When dating, you are the boss. You decide who isn't worthy of your time, and who lives to fight another date.

You may like to take the approach that, only if someone has passed your test do they earn the chance to learn more about you, and in turn, more about your artificial nutrition. By taking this approach you remain firmly in charge, and only those who you form a bond with will be privy to your personal information.

Be cautious, and remember you're the boss

However you decide to approach internet dating, only share the information you are comfortable with sharing, and make sure to put yourself first; protecting yourself from potential hurt.

I'm in a relationship:

Illness of any kind is an acid test for a relationship.

Whilst some partners will be able to handle and come to terms with your illness and artificial nutrition, others will not have the facility to be able to cope with such a big change.

For some couples such adversity will strengthen their relationship, but for others the extra pressures will be too much.

The breakdown of your relationship can be a particularly painful blow at a time when you are no doubt already feeling vulnerable.

Read about the impact that artificial nutrition has had on Mark and Jackie's relationship.



Inextricably linked – A carer's perspective:

How does life change when confronted with emergency surgery and the impact on the carer? How do you prepare for life with TPN, ileostomy and Mucous fistula when catastrophic circumstances dictate this is your path?

If I had to answer these questions prior to January 9th, 2016, I would have said you're talking to the wrong person that's not us.

We cannot dictate the course of our lives, but with some PMA (Positive mental attitude) and good help and guidance the journey can become slightly smoother. For us TPN is for life and has given my wife; Jackie, life. With only 60cm of short bowel left and no large bowel due to adhesions on scar tissue and going into septic shock, Jackie has been left unable to absorb life needed nutrients. Two months after the admission: days visiting Intensive care and High dependency unit and Intestinal failure Ward, we were home.

We always said little steps make a stride. Each day we talk about where we are, we are brutally honest with each other. The highs have been the time we now spend together, living life in somewhat more structured style than we used to.

My being able to do Jackie's TPN administration and dressing changes has given us a less rigid timing regime than waiting for nurses arriving.

We have learnt a lot along the way, unfortunately not always from the professionals.

Every case is different, in a tick box society square pegs won't always fit in small round holes. So, to us the lows are the continual battle against government bureaucracy.

The voice for TPN patients is very small, the awareness is not yet high profile.

There is a long way to go with both practical things (stoma wear, line protection for showering and bathing), and with the open discussion of important "taboo" subjects: Sexual relationships, power of attorney and wills, life with and without your partner.

When the caring stops life has stopped.

(Written by Mark; carer to wife Jackie)

Intimacy

The thought of sharing your body with another person can be daunting and may be associated with negative thoughts and worries.

You may not look the way that you used to, but difference can be a good thing.

You have a beautifully unique canvas...

- **Make sure that you're at home in your own skin first.**
- **Talk about your anxieties/concerns openly with your partner**

Illness and beauty are not typically described as synonymous, but there is something very special about your scars, tubes and bags.

Your body tells a story; your story.

Where others may struggle to expose and share their most formative experiences with their partner, your body has its own voice; and it is strong. Your scars provide the perfect segway to talk openly about topics that are important to you.

Once you are at home in your own skin, there is nothing to hold you back from enjoying intimacy in your relationships as you did before.



Taking ownership of your health and nutrition

“

Do not be afraid to ask your Dr questions—It is your right to know about your own health!

(26yr old (F)
PN every night)

“

It is critical to take responsibility for your central line. It is your LIFE LINE!

(26 yr old (F),
PN every night)

The prospect of managing your own artificial nutrition can be daunting, but with taking ownership of your own treatment comes freedom, and endless possibilities.

You may be lucky enough to have the backing of fantastic health care professionals, and supportive friends and family, but no-one will ever be a better advocate for you than YOU.

In order to unlock your full potential, you must first be willing to, (as much as is possible,) take responsibility for your own health.

Although they mean well, you may encounter situations where health care professionals approach your line in a way that you do not feel is safe.

If this ever happens to you, you must take ownership of the situation.

It is ok to say NO!

Nothing can be more important than your health.

Sometimes when you are rushing to get ready for an engagement you may be tempted to take short cuts in setting up your artificial nutrition.

It is important to remember that whatever it is you are late for, whatever pressures that you feel that you are under, your safety and care in setting up your feed trumps any other pressures every time!

Never be tempted to take short cuts, and don't be afraid to tell people that other things can wait.

Once you have mastered your artificial nutrition, the opportunities are endless.

“

I have competed in show- jumping, love to travel, have a degree in food marketing, and recently went back to college to do a degree in psychotherapy.

(26 yr old (F),
PN every night)

“

Initially planning a long trip was daunting; preparing the equipment, organising medical travel documents and finding the right insurance... but once all the preparations were done I had the best month and a priceless sense of freedom

“

Since starting PN I have graduated with a BSc, continued with my medical degree, got back into running and climbing, travelled, and met my boyfriend.

It's no exaggeration to say that I've never been happier

(25 yr old (F) PN 7 nights/Wk)

My story

“

My Mam said from being born I have been artificially fed.

I had a Gastrostomy then a Jejunostomy, and just before I was 10 I started TPN - I was less than 2 stone and had age 4-5 clothes - always the smallest at school, even smaller than the reception class! I didn't mind that I was attached to a drip: not that much different to the kangaroo pack I had before (only scrub up and line care different), and I grew and put on weight - I was happy.

I travelled around 10 miles to school. I'm Deaf and sign, so my friends didn't live nearby - I sometimes had people to sleep over or come if we had a night away with my family - I never stayed at a friend's (I was never invited).

When I'm in hospital my Mam stays as I get lonely and can't communicate, but then I think of all the good things I have done - I went on dream flight to America and had a 'make a wish' to be Newcastle manager for a day.

My friends come to see me and do visit me in hospital when I'm poorly. I have a little time off my PN on Thursday night for the Deaf club.

So, I guess I accept I'm a little different to other people, but with a bit of planning I can do lots of things too.

TPN around my life, not life around TPN.

Signed by Ryan (wrote by Mam)

“

I became ill during my teenage years and my education suffered greatly. I started work after leaving school but sadly poor-health limited my working career. Often off work with a 'bad belly'. I found myself having a major operation following complications after some routine tests. My employer agreed to hold my position open for as long as possible. The office I worked in was busy, very busy so to cover the workload they employed a temp from an agency. She covered my position and when I was able to return to work they extended her contract, so I could ease back into work.

I found it more difficult than I expected, I was seriously malnourished at that point but was determined to struggle on. I became friends with the temp, Helen, and when I discovered she lived just around the corner from me we got friendly and she often dropped me off at home after work. I think she could tell each day was a struggle. We became friends and I went around for dinner a few times. I met her son and we got to know each other and started dating. Our courtship wasn't normal, no dinners and trips to the pub, I vomited every time I ate or drank. To cut a long story short, I was admitted to hospital and at my lowest point I told him it was okay for him to go and find someone normal. I didn't want him to feel trapped in a situation he would regret. He said he wasn't going anywhere. I somehow proposed (not entirely intentionally) and that was that; we became man and wife a year later. Between the proposal and wedding I had a terrible time recovering from surgery; he stood by me, often with a bucket for me to be sick in! He has seen how PN has made me stronger and following the surgery my symptoms have improved. We have a wonderful life together and I know I couldn't have come this far without him.

(Lynne)

Useful resources



PINNT – www.pinnt.com

Mindfulness apps:

- Headspace
- Calm

Chronic pain apps:

- Curable

Books:

- The Happiness Trap – Russ Harris
- Living with the Enemy – Ray Owen
- The Reality Slap – Russ Harris
- The Grief Recovery Handbook – James & Friedman

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