

WELCOME TO THE NET CLUB-

*“IT’S A LIFE
MEMBERSHIP SORT
OF THING!”*

This is a compendium of real stories from real people, all of whom either have a NET or a direct connection to one who does and have been through what you are going through right now.

We have compiled it to help you and to give you support and essentially hope for the future through our own lived experiences.

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Brian's story

My name is Brian and I am 62 years old.

In the early 2000's, I complained of an upset stomach regularly and had to seek help from my GP. It was never bad enough to cause major alarm, but it was annoying to say the least. I trundled on with it for some time, blaming diet, work stress etc. While they may have been the base causes, there was something else going on which was not in my stomach that I didn't realise.

Eventually, on discussing it with my GP, he referred me to a Consultant for further tests. I travelled to Cork and was referred on to the Bon Secours Hospital for an Ultra Sound. When the lady carrying out this procedure repeated the process and then excused herself to consult with her superior, I knew, good or bad, something had been discovered. After another run through, they advised that they could see a shadow that should not be there.

A raft of tests then followed over time and finally I was diagnosed with Neuro Endocrine Tumours of the Pancreas, but I was not informed. I did not have an Oncologist at this stage obviously and it struck me as unusual that nobody I met seemed in a position to confirm my fears. When I met my Surgeon, he took on the responsibility. I remember having a premonition of what was about to be announced and knowing it was going to be major, but I was prepared in my head. I knew my wife was oblivious to it and I had to turn to take her hand in advance consolation.

The next really tough part was telling my son and daughter. They were 21 and 18 at the time, University and Leaving Cert.

I was prepared in my head, I now believe, as I had walked a portion of the Camino de Santiago a couple of years previously. I had built up a lot of stress within me and I felt so much better and so much more in control after my adventure in Spain. I recommend it, whether you are religious or otherwise.

I was dealt with pretty promptly and I had my surgery in 2011 to remove the body of my Pancreas, my Spleen and a cluster of tumours that were wrapped around one Kidney. The Surgeon had expected to remove the Kidney also, but he was able to save it, God bless him. I had a later, smaller procedure to remove my Gall Bladder as well.

All in all, a traumatic experience, but with positivity it is possible to battle through.

Since 2011, I have been receiving a monthly Sandostatin injection to treat a number of “spots” that appeared on my Liver.

Until October 2020 that is, when I received word that I have been accepted for PRRT treatment in Rotterdam beginning on 21st January 2021. My previous injection treatment was “long acting” and had to cease pending Rotterdam but had been replaced by three daily injections of the “short acting” version. I started on Christmas Eve and that took a little getting used to.

I have now completed four trips to Erasmus MC in Rotterdam and have been advised after scans two months later that there has been a 50 to 60% reduction in disease, which is fantastic news.

The trauma of the diagnosis announcement, particularly the fear that the word “cancer” instills is very difficult to deal with and is a very individual challenge. My head seemed to be in the right place following my Camino walk but I overlooked my wife’s trauma. Sure, I was the patient!! But that’s not how it works. If you are fortunate enough to have a loving partner or friend, who rows in with you, they too are on the same road with much the same psychological suffering as you. At my first Patients Forum I met Tommie Gorman who understood this and spoke to my wife for maybe 20 minutes.

Whatever he said, brought a lot of ease to her anxieties in those early days.

I found that positivity and keeping active were great helps to me. My outlook was that I was not a medical professional so I should rely on their direction at all times. That does not mean that a little prodding

and reminding can't be used. I tried to understand as much as I could without querying in any negative way.

Initially, newspapers, crosswords and tv occupied me.

I have to say that well meaning visitors can be very tiring and if allowed at all, should be restricted to short periods, especially early on. They just wear you out.

When I was able, I found walks in the fresh air were great for attitude, appetite, sleeping pattern and just a change of scenery.

While relying heavily on medical professionals, I learned that their expertise may not stretch far beyond that. When my trips for treatment abroad were to be organised, which happened during heavy Covid restrictions, a family member or two, preferably young, are better prepared for the logistics of travel etc.

Also, I was of the impression that all out of pocket expenses were covered by the scheme. This is not quite the case and if one were short of funds it could raise issues. This great scheme covers the hospital abroad and the treatment provided (substantial) and flights (Ryanair specify baggage separately so they don't cover that). They do not cover accommodation, taxis, airport parking etc. They initially refused to cover Covid tests of €500/€600 per trip but eventually relented and paid €75 per test for patient only. I spent, on myself and my wife, up to €10k on four trips outside of medical which was paid direct. I was refunded just less than €1,500. I won't starve, but this could be an issue for some.

I have had a number of side effects since my latest treatment not least of which is my body no longer processes any fat. Now I am on Creon to be taken with food and am trying to get the balance right.

I will shortly be resuming my Somatuline Autogel monthly injection as well.

BS October 2021

Adrian's Story..

It began for me in June 2018 with a pain in my side. At 9 am my GP could feel something, sent me for a scan, who then sent me for an x-ray and suggested that my wife come with me to the hospital.

Then by 2.30 pm- BOOM- pancreatic cancer, secondaries in your liver- you definitely have 6 weeks , probably not 3 months, we are sending you to Dublin for tests, get a power of attorney made ...

So much noise-

I was grand this morning, I just had a pain!!

The next 4 weeks were a blur as the trip began. There are no words for it. I got some great advice along the way then...

Rely on texting to communicate your news rather than telephone calls; it means you are less likely to lose it.

Start a hard cover diary or notebook to record what you have been told, times for the next appointments and so on.

You don't take in this stuff , so write it down, take the notes. Bring the book with you to every appointment, and if it's one of the ones that has a flap for papers in the back, better again.

I have found the book stops me catastrophizing – in my head, making things worse than they are in reality. You can go back to the facts, what was said, who said it, and when.

Also , a time will come when you learn how to shut the book for a bit and give your head a rest.

You aren't in control of your own diary anymore (Being self-employed, I found this difficult). They say when you are to turn up, the system sets the pace, so learn to go with the flow.

I had to learn this “going with the flow” stuff and my GP recommended counselling. That was another first for me. The way he put it was “Adrian you wouldn't try and drive a racing car without

learning how. You need to learn how to deal with this, it's your new reality, so think of counselling as teaching- you need to be taught how to deal with all this"

It was a great suggestion, I did it and learned a lot about how to deal with it.(I believe there are counsellors and counsellors so make sure you get a recommendation.)

Other tips, I wish I hadn't told so many people; it's very hard on your partner, your family and your close friends when well-intentioned sympathizers come up to them unannounced and download yet more grief. They mean well but it hurts the listener, so my advice is to say nothing until your treatment plan is clear and there is a path forward. There will be. The line we now use in my house is "We are dealing with it ,Thanks"

After a while, it dawned on me that I didn't get this cancer on a day in June 2018, that's just when I was told about it. I had it before then, June 2018 was when the fix started.

I have always found that the antidote to stress is purposeful action, and if you can, try and think about your diagnosis as the first real step forward. This is a big ask, it's a real shift in how you look at things and it took a few years for me.

Looking at it this way makes it easier though. I hope this helps

AH October 2021

Adrienne's Story

Writing this in Uppsala on first day of last treatment.

I want to talk about what I learned about self-care and nurturing myself. Tried for a long time to keep going as normal as if nothing was wrong.

This is something we all know but need reminding of on a regular basis. It is very easy to lose ourselves in the maelstrom of our illness.

Points to remember:-

1. Stop and listen to your body. Get to listen to what YOU need.
2. Choose what really matters to you and let as much as possible go. We don't have control over much. Focus on what we can control.
2. Don't be too hard on yourself. We are all dealing with challenges and the fear of the unknown.

Mental Health Matters.

1. Try as much as possible to stay connected with friends/ family. A simple text will do on days that you are not up to conversation.
2. Have realistic expectations about what you can do on any given day. Listen to your body. No one can tell you how you should be feeling/ or what you should be doing.
3. Spend a little special time every day doing something for yourself. Something that brings you joy. A walk. A nice bath, looking at favourite photos etc
4. Have you ever tried writing a diary? Write down 3 positive things that happened to you that day. The comfort of a pet, a gesture from a friend, a tasty meal. These entries will support you on days that you are feeling down.
4. Exercise. Try and move a little every day. Even a gentle walk in the garden admiring nature will fill your heart with joy.
5. Sleep/ Eat well whenever you can.

6. Feeling anxious/overwhelmed? Writing down your feelings can give you control over them.

7. Try meditation. Focusing on the present moment and on your breath is very beneficial to our overall health. At first this will seem v difficult as all kinds of thoughts will intrude. Let them go. There are many free apps that can help Google 10 minute meditation. Other good apps include The Daily Calm, The Honest Guys, The sanctuary Dublin also hold free meditation sessions for everyone and the mindfulness centre supports free guided meditation, they are excellent.

9. Explore the possibility of having a massage. Gentle touch and emotional holding cannot be underestimated when living with stress. Massage can also manage the physical symptoms of anxiety such as depression/ insomnia/overactive mind. Please check that the therapist is properly trained and has cancer care experience.

10. Lastly embrace the fantastic support and friendship that this group has to offer.

AG October 2021

Mary's Story

Unfortunately, in my case my diagnosis was very late and completely by accident.

I had been very ill for many years and had experienced so many signs and symptoms for many years, that were never put together.

I started to attend a different GP in my GP practice clinic who, instead of just prescribing medication, actually listened to me and referred me to a stomach specialist, as she suspected I had Gallstones.

Unfortunately, I had to wait 18 months and then 6 months for a CT scan, which showed that I did have gallstones, but it also showed my lower right lung lobe had a lot of tumours.

What I have learned in over 9 years since I was diagnosed with Lung Neuroendocrine Tumour Cancer and Carcinoid Syndrome is to keep asking questions and to find out as much information about your disease yourself and not be afraid to speak up about your personal situation.

Try to speak to other patients and join support groups.

You will need support from family and friends living with disease, so don't be afraid to ask for it.

Be careful of people who say that they healed themselves by trying alternative medicines, diets, juices etc.

They can do more damage than any good.

Try to stay positive and live one day at a time.

I would like to add that I had not been properly investigated and misdiagnosed with another illness before I got my correct diagnosis.

I had been sick for years with chest infections, pneumonia, pleurisy and bronchitis.

But, my GP had never sent me for a chest x-ray or investigate why this was happening.

I had been told that I had IBS and I was being prescribed meds for this, but nothing was being done to find out why my symptoms had gotten a lot worse and more frequent.

I had been told that I was possible in early menopause even though my blood hormonal level was normal.

I had a rapid heartbeat at times, swollen ankles, unexplained weight gain, which were all signs and symptoms of my Neuroendocrine Tumour Cancer.

So, my advice is to find a GP who will listen to you and investigate what is going on.

I would like to add that when I was diagnosed in 2012, I found it all so confusing and hard to believe my diagnosis.

As first I was told by the Lung Specialist who did my bronchoscopy that I had Carcinoid cancer.

Then on my next appointment he said I hadn't got cancer.

I was so confused about things that I rang the Irish Cancer Society to ask for information about Carcinoid cancer, only to be told by the person on the other side of the phone that they never heard of Carcinoid cancer and they couldn't help me.

I made a decision to find out as much information as I could myself from reliable medical sources.

I set up alerts in Google so that if anything new came up, I could read it.

I also think that patients should bring someone with them when they are attending appointments.

I find it good to write down any questions in a notebook and leave a space for a answer.

I bring the notebook with me, so I can ask the question and make a quick note of the answer under each question.

As I found that when I came out from appointments, I realized that I had forgotten to ask important information.

Because I have been diagnosed with Carcinoid Syndrome, as well as Lung Neuroendocrine tumour Cancer. It can be hard on myself and my husband at times.

But, the best way to get through this is to be open and honest with each other and support one another when one of us is having a bad day.

I find walking great and I find mindful walking very good to calm my mind. I also find Yoga and Tai Chi very good.

There are some free Yoga and Tai Chi classes available for cancer patients from Arc House.

They are also very good online classes available.

That's all for now.

M O B October 2021

FIONA'S Story

My name is Fiona and I was diagnosed with NETS in April 2017.

My diagnosis started in November 2016 when I fell and broke my wrist, had to have chest x ray before general anesthetic to put plate in.

A lump showed up somewhere near my liver and over the next few months had all sorts of tests until a biopsy and specialised blood test showed it was NETS.

I was devastated to hear the word cancer after been told many times that it wasn't. I had absolutely no symptoms.

A couple of days later I had a liver resection and was in hospital for a week. Am not gonna lie, it was tough.

But the good news is that when I recovered from that and learned more about NETS you realise that you can live a relatively normal life. I got wonderful care and still am, in Tallaght Hospital.

Everyone is different but for me, the thing that helped the most was counselling. I contacted a cancer charity and had 8 sessions with a wonderful Councillor.

Hope this is helpful.

Fiona

FR October 2021

ROSAMOND'S Story

A NET experience from diagnosis Aug, 2008 – to date (Oct. 2021)

2008

Apr. Routine blood tests showed high Gamma GT . GP said usually caused by excess alcohol consumption, though I'd never had more than the odd glass of

wine on special occasions. Advice cease all alcohol however small the amount/or infrequent consumption.

2008

Aug. Further blood test showed Gamma GT levels had *doubled*. Referred to St. Vincent's. There followed three months of tests, ultra sound, 24hr urine collection, many scans and finally biopsy of the liver which confirmed multiple abdominal tumours. Decision to send sample to Belfast as suspected Neuro-Endocrine origin and this was confirmed end of November. Whipples operation recommended: to be done in two halves allowing time for recovery in between. (this plan was overtaken by events see below)

2008

Dec. Whipples operation in St Vincent's to remove half the pancreas, and parts of several other organs. Too big an operation to do all that was required in one go so mets on liver to be done when I'd recovered from this operation.

Dec 31 A day before I was due to go home had a sudden serious internal haemorrhage. Rushed to ICU 5 days and while there emergency ileostomy created, as much of the colon had to be removed. Told I was lucky to have been in hospital as would have died if I'd been at home.

2009

Jan/Feb. Recovery from Whipples slow from set- back. Radiation beads were inserted on hopes of reducing liver mets.

2009

Mid-March Another crisis: abcess on liver developed necessitating resection of whole of right side of liver much sooner than envisaged. After liver resection very slow recovery and regaining of strength – physiotherapy to rebuild muscles and efforts to regain a bit of weight plus lengthy courses of intravenous antibiotics to treat infection.

2009

June 9 After six months in hospital finally returned home! Weak as a kitten so carers needed for the first month because living on my own, then hours reduced gradually until Christmas when I was able to manage.

2010 intermittent bile duct problems caused by either stricture or stone requiring pigtail drain for 3 months(managed at home)

2011

Aug. Three lesions in the liver identified , bile duct improved

Oct.7 Liver surgery to remove lesions plus access point (small disc) inserted to allow easier access to bile duct if necessary in future

Oct.31 Bile duct stricture - new access point used to insert tube for bile duct drain

2012

Jan. Started Lanreotide injections 120mg every 28 days. Continued for 4 years. This affected blood sugar levels. Was put on 2 drugs in attempt to stabilise blood sugars. Both had bad effects of diarrhoea so have managed by strict attention to diet. After 4 years one lesion remaining in liver growing so... as it is inoperable due to position near a major blood vessel

In 2016

Feb –Apr offered clinical trial to explore if Lanreotide injections given every 14 days (instead of every 28 days) would make a difference. When no change observed in lesion size after three months, was taken off the trial. Advised best option now was oral chemotherapy

July Started on CapTem chemotherapy (oral tablets) 28 day cycle: a fortnight on tablets then a fortnight's rest. Treatment seemed to check growth of tumour/lesion

2018

Nov. Captem halted because of sudden appearance of extensive rash from thighs to ankle. Oncologist could not explain as unlikely to have been caused by the chemotherapy

Referred to dermatologist Feb 2019 but since rash had disappeared she could not explain it.

2020

Sept Regular scan (six monthly) showed further growth in liver lesion. Referred to radiotherapist for Stereotactic Body RadioTherapy (SBRT) in *Dec 2020*. Initial scan taken three months after treatment (*Mar 2021*) showed no change but further scan three months after that showed a very slight reduction in

size. Now *Oct 2021* I'm at present waiting for a third follow-up scan as radiotherapist thinks there may yet possibly be some further improvement.

Like so many others in the NET patient group I never know what's next in my NET journey but I feel very fortunate to have survived so far and hope the excellent team in the St. Vincent's Net Clinic will still have some more tricks up their sleeves for all of us.

RVP

October 2021

HELEN'S Story

I first heard the news I had NET's (formally carcinoid) in March 2009 just three weeks after having my second child.

I had been ill during my pregnancy, but it never occurred to me I could potentially have cancer.

I received the news by telephone by my respiratory physician, the news didn't sink in. "Carcinoid? What's that?" I went off to collect my first born from school and pushed my news to the side and put my mammy hat on. I rung my husband and informed him and my parents, still not processing the severity of the illness I had been labelled as having.

Even two weeks later at an appointment to see a lung surgeon who was going to do my lobectomy on my right lung, I was either in denial or overwhelmed. I had only given birth I was meant to be enjoying the postnatal period with my beautiful baby girl. My very good friend (who was also at the birth of my daughter) came with me to my appointment, the surgeon mentioned the word 'Carcinoid my head was working out carcinoma-carcinoid?

"Oh it's cancer!"

Then my fight begun, get all the info you can, Google, contact Irish cancer society, charities in the UK sent me a brochure. I could not find anything in Ireland, so I kept in touch with neuroendocrine cancer UK.

My friends and family supported me, but I didn't want pity "You poor thing", I wanted to get better.

My surgery was delayed for four months so I could enjoy motherhood, enjoy! I did though though the surgery was at the back of my mind I had a distraction with my two adorable children.

Surgery was cancelled on the day, all the preparation, getting the children organised and my mental health prepared. Two weeks later I eventually had the surgery, I recovered well, they said because I was young (31). I could not wait to go home but I had to be ready. One Dr pushed me to go home on the Friday after surgery on the Tuesday, I wasn't physically ready, and he got a surprise on the following Monday seeing me in the hospital bed. That's when my intuition and my assertiveness fight begun.

To the new patients reading my story, I've had a long journey (that's how I describe it) and I continue to do so. I've had to fight; be assertive for the standard of care I deserve. There has been flaws, I've had my 'why me?' and feeling sorry for myself moments. However, I bounce back it might take a few hours/days but I continue to plod on.

I don't like the word disease (too negative for me), I'm all for mindfulness, yoga, self-care courses, counselling all of these have helped me hugely over the years. Ireland has come a long way since I was diagnosed 12 years ago, we have a website, a committee, annual patient days and NET centre of excellence clinic that I am thankful to attend.

I'm getting emotional writing this but I'm passionate to be an advocate and support others in this journey we all take.

HG October 2021

Tom's story

I was diagnosed in 2007: it was a bolt from the blue. The Certificate examinations were underway in our school, and I had the responsibility for all arrangements involved, so when I set out for Barrington's Hospital for tests ordered by my G P, I was more concerned with my job than about my health.

A colonoscopy, gastroscopy and an ultrasound of the liver revealed problems. There followed weeks of further scans and tests before N E Ts were diagnosed. The Doctor did his best to cushion the blow by explaining that as cancers go, this is the best one as it's treatable!

As my liver's left lobe was badly damaged, A liver surgeon in the Mater Hospital was my next port of call. I was urged to take the Public System as the better option for the future. On August 14th the Leaving Cert. Examination results were out but my wife and I were heading to Dublin on the 7.28am train from Limerick Junction. After an Octreotide Scan I was informed that Uppsala was on the cards for me: they could tackle part of the surgery but Radio Frequency Ablation was also required, a treatment not then available in Ireland. His advice was to have all the treatment done in Uppsala assuring me that, "...you won't be disappointed there."

When cancer crash-lands into our lives it has scant regard for the circumstances in which it finds us. For my wife Maria it was an especially challenging time. Her mother was staying in our house living through the final weeks of her terminal liver cancer. On August 27th she passed away. The day after her funeral Maria and I were off again to Dublin on the early train, for further scans at the Mater. Cancer shows no mercy and offers no exceptions for difficult circumstances!

The month of September was spent preparing for the Uppsala surgery by getting as much walking exercise as was comfortable. Word came through from Sweden that I was to be there on Monday 5th November. We travelled to Arlanda airport from Cork on Friday 3rd via Heathrow. The bus to Uppsala delivered us through the sleety dark, suitcases in tow, to perishing cold, slushy streets and a massive, packed, bicycle park. However, if the weather was cold the welcome Monday morning greeting from the Doctor and his nurses at the hospital, was positive and life-affirming.

The surgery, following 3 prep. Days, was successful and I was given a detailed account of his labours: all but 2 percent of my tumour burden had been removed and my cancer clock had been wound back. Because of my psoriatic arthritis, I wasn't deemed suitable for Interferon, the preferred treatment, so a Sandostatin Lar, 30mg injection every 28 days was prescribed. The recovery passed without a hitch, and we landed at Dublin airport on 21st November complete with 51 metal clips tattooing my scar!

In January 2008 I was back in Uppsala again for further, planned Radio Frequency Ablation treatment. I was awakening from the general anaesthetic when I suffered sudden, severe respiratory difficulties. Cue instant urgent action in the operating theatre; all tubes were hastily removed from airways and with the help of an oxygen mask, I was able to breathe normally again. On enquiring about this alarming event, I learned that it was a Carcinoid Crisis episode in line with my Carcinoid Syndrome! The Doctor gave me a full heads-up on the risks involved with this Syndrome, especially regarding surgery and general anaesthetics. I told him that this was my second such episode; the first was in 2004 after surgery in Cork for a detached retina! He strongly advised me to wear a bracelet or neck-chain pendant to advise/warn medics, in the event of future surgery/anaesthetic and to contact him by mobile, if I ever needed help. Unfortunately, it was a call I had to make!

For the next 4 years I visited Uppsala every 6 months for monitoring bloods, scans, 5HIAA urine tests and meetings with the Doctor. Maria and I got to know Uppsala really well. There was one blip, however, in the normally high standard performance of our hosts. Totally unexpectedly, I got an email from the hospital to travel for further Radio Frequency Ablation of liver tumours. We were shocked but duly made the relevant arrangements and arrived worried but on time at the hotel, ready for admittance the following morning to the hospital. I was prepped for surgery, placed on the trolley for transport to the theatre, when a meeting of the medics in charge was called. Within minutes I was informed that there was an error in reading my scans: the rogue tumours had already been treated! I was off the hook! There were profuse apologies offered and accepted. As far as I was concerned, the good news that there were no new tumours was well worth a trip to Uppsala. Anyway, I owed my life to these kind people; to err is human.

Having been advised at the beginning of my patient journey, not to dive into the internet seeking information on liver cancer, on returning from my second trip to Uppsala I decided to take the plunge. All sites advised NETs patients to seek support groups, so I was delighted when a meeting of NETs patients was organised for U C C. It was the beginning of the NETs Patient Network inspired by Tommie Gorman's drive and experience. I met Tommie first in November 2007 in Uppsala only days after my surgery. His decency, survivorship skills, trust in the Uppsala medics and shining empathy filled me with hope. Tommie was the personification of where I aimed to be!

Surgery was required on my prostate in 2012. The urologist was well aware of my Carcinoid Syndrome, and we agreed to an epidural as anaesthetic with octreotide infusion. I rang Uppsala for guidance. The Doctor strongly advised me to have an octreotide infusion on standby in the theatre for instant use, in the event of another Carcinoid Crisis episode. The night before the surgery I

requested a visit from the anaesthetist to discuss the epidural and further arrangements. There was no mention of the octreotide until I raised it. He was loathe to accede; it was only when I said there would be no surgery without it, that he agreed to provide the octreotide. I had the surgery the following morning with a different anaesthetist in charge. He was also none too keen to use the infusion: it could do as much harm as good, was his opinion! The surgery was successful and there were no complications. A few years later I had no such difficulties when kidney stones were removed. Ours is an uncommon cancer so, we need to be as knowledgeable about our condition as possible.

In 2013 also I was invited to join a group in my hometown of Tipperary, with the aim of setting up a cancer support centre. The involvement was good for me and the committee I joined were young and progressive. Today Tipperary has a 1 million euro, fit for purpose, modern cancer support centre to serve people and families affected by cancer. There's no debt to be serviced thanks to the generosity of the local community, our wider catchment area, private and public donations as well as European Funding. I'm a member of the Men's Support Group that meets twice monthly. We discuss in strict confidence all the challenges our various types of cancer pose. However, betimes cancer takes a back seat. Local and national affairs, often sporting, sometimes political but always entertaining can dominate. Anecdotes, usually laugh out loud comical, are related nightly without fail; a tip for an equine certainty during Cheltenham, Leopardstown or anytime is always likely! We're there for one another, no matter what.

I've had a lifetime commitment with the GAA. and when the cancer struck, I was lucky to have it. My passion was training and coaching under 6-, 8- and 10-year-old boys on Saturday and Sunday mornings. There was no time to dwell on cancer fatigue, never mind scans or tests with 20 plus joyous, positive budding hurling and football stars to be guided, coached: above all, enjoyed! This was mindfulness on steroids and the energy overflow I experienced, lifted my spirits week in week out.

When the Centre of Excellence at St Vincent's Hospital, Dublin opened in 2013 my wife and I were delighted. Dr Dermot O'Toole, a NETs specialist with a European reputation, was just the man to lead the new set-up. Uppsala was a treatment lifesaver for us but it was too far away and too costly as a monitoring centre. Travel to Uppsala was a full day affair; the train had us in Dublin in 1 hour and 35 minutes. The airport bus took a further 45 minutes and approximately 3 hours later the 2 hours 40 minutes flight began. It took another 35 minutes travel to reach Uppsala...tired. Our visits up to 2011 cost us 20k at the very least, as the treatment and monitoring alone were covered for us, by the Travel Abroad Scheme. The travel and hotel we had to pay ourselves! With the monitoring in Dublin, we avail of my Services Card for free travel by train, bus

or Luas and such is the connectivity, we're at the hospital in under 2 hours and 30 minutes. Even when I feel unwell, it's not at all taxing.

I have confidence in the team at the Centre of Excellence in St Vincent's. Professor Dermot O'Toole is an acknowledged N E Ts expert with an international reputation. Professor Donal O Shea is an endocrinologist who has worked wonders in his field. They head-up our team of medics and despite the challenges they face in our medical system, manage to run a good ship. If I need prescription renewal or to order bloods, scans or the 5HIAA I email Lisa on a Wednesday and she will reply on Thursday or Friday. The prescription will be posted or arrangements for scans, bloods etc. will be made. As most of my scans are planned months in advance, delays are rare, up to now anyway.

In September 2019 I travelled to Uppsala for PRRT on the advice of the team at St Vincent's. There were 3 further trips to complete the therapy, 6 weeks between them. My doctors believe my cancer began sometime in the 1990s so my diagnosis in 2007 was a late one. Fatigue is my most difficult symptom therefore travelling from Uppsala after the treatment was challenging. People can feel very unwell for a time after treatment. Sitting in a plane for almost 3 hours is not ideal in such circumstances. I was lucky to escape without nausea until after the final treatment. I was doubly lucky to be at home when the sickness started. It lasted for 6 hours. How I'd have managed if it began in the plane or at either airport, with hours of further travel ahead, I do not know. The PRRT stabilised miraculously my multiple tumours; I was hoping for shrinkage but that was not to be. As the doctor said to me: "The tumours changed colour. That's a good sign"!

How lucky we are to have access to PRRT but surely we shouldn't have to travel abroad to avail of it, at enormous expense to the public purse. So, it's with great anticipation that we await the setting up of an Irish PRRT centre in St Vincent's NETs Centre of Excellence. We, sick, vulnerable N E Ts patients demand it!

T O'D October 2021

Eoin's Story

Throughout these stories a constant theme has been the effect on family, who are equally impacted by the new diagnosis. Eoin is one such person and here are the things he has learned along the way...

You need to be the expert in your NET.

Because of its rarity, you need to be your own expert, only letting the medical professionals manage your disease, will cause unneeded issues.

Ask questions, join online groups for your particular NET & for just NETs. Research and use the INCA web site, incalliance.org to get information.

Be selective with which Online Groups you use for information.

Online groups are a matter of taste, so I won't name any, but after you join an online group, take the time to read a selection of past posts.

You will find a mixture of "free for all" that allow people to post fake cures, alternative treatments (that don't work) etc., to "I'm the owner of the group, so I only allow posts I like, to be posted in the group", so you get an opinion, rather than the facts.

Leave any group that you don't like, staying will probably affect your mental health.

NETs is lifelong, you need to integrate your new regime into your life.

In my opinion, the best way to live well with NETs, is to integrate your new regime into your life.

There are proven routes of treatment for nearly all NETs and once your NET specialist has identified yours, he/she will explain to you in medical terms. You can find out from other patients with the same NET, what that route is in plain English.

It is a natural reaction to try to research cures and with the amount of people trying to make money from fake cures, it will be difficult to avoid seeing them.

Steve Jobs is probably all the proof you will need, he decided not to go down the proven route, (i.e. Advice from multiple NET specialists), instead, because of very bad advice, he tried everything that a Quack sold him and it didn't help.

There are some alternative medicine options for side effects of treatments, but

these are not cures. So no matter what you read online, or you are told by a “Healer”, stick to the proven route.

Run from any medical professional that will not have your file reviewed by the NET Centre of Excellence in St. Vincent's Hospital, Dublin

This still happens. A medical professional or consultant decides that they know best, they have you covered, there is no need to see a NET Specialist, or they just don't mention a NET Specialist.

Ask them to have your file reviewed in St. Vincent's Centre of Excellence, if they refuse, say goodbye.

Ask your GP to change your care to the Centre of Excellence.

If your GP refuses, contact the Centre of Excellence yourself.

This is YOUR Life, don't be afraid of hurting someone's feelings

You will need to learn to speak up or have a carer/family member do it for you. The majority of the time you will need to do this when having tests, etc, but can happen during a consultation.

You deserve to be treated with respect and have every right to make someone aware of it.

For example, during a consultation, it is easy to get confused, don't just let it go, ask the consultant to explain it to you again, maybe in non-medical jargon.

Another example, you could be getting an intravenous catheter or cannula in your arm before a test, invoke the 3 strike rule, if the person doing it can't get a vein in 3 tries, ask for someone else, and stand your ground.

For times that it seems no one can do it, ask to have someone from the phlebotomy Dept., (they take blood all day long), pronounced [FLUH] + [BOT] + [UH] + [MEE] -

Start a Journal to take notes.

A lot is going to happen in the coming years & you will be in a far better situation if you have your own notes to keep track.

Always try to bring someone & your journal to any appointments.

It would surprise you how much you forget after an appointment, take notes

Medical Professionals are not divinity.

Medical Professionals are people who have decided to make their Medicine Career.

Yes, it is a very worthy profession and takes years of hard work & study, but they are not anointed, it is probably not their vocation and the majority are not geniuses.

They are human.

Don't get me wrong, you will probably come across one or two that you find are all three, but it's a rarity.

Talk with them, ask them questions, question them if you don't understand something and don't accept a brush off.

You will probably know more about NETs than non-NETs medical professionals.

After doing just a little research on NETs yourself, you will probably know more about NETs than all non-NETs medical professionals.

This is not their fault, they have a lot of information to keep in their heads, so the rarer diseases seldom get looked at.

Which brings us to

Don't believe everything you hear from a (non NET) consultant.

For some reason, many consultants who are not NETs specialists will say that they know about NETs, but they do not.

Some surgeons, after they have operated, will even tell you that "you are now cured".

There is no cure for NETs.

Make notes & confirm with your NET specialist

Stop trying to “get back to normal”.

You will get back to “A” Normal, but it may not be the same as the normal you had before you were diagnosed.

Accept that and you will avoid a lot of frustration.

For Carers/Family members

- You can make a huge difference to a NET Patient on this journey, if you become part of it.
NETs is not the same as most other cancers, it’s not an “event” that happens & passes, it is lifelong.

Some people do get lucky and after surgery, they can go back to almost normal, but many have to integrate regular tests, scans, treatments & surgeries into their lives.

They will need help to do this.

- For a patient who understands technology, an online calendar works fine. The settings I have found to work are to set an alarm for 2 days before, the day before & a time on the day that would give you enough time to get there.

For a patient who does not understand technology, the best options are a Diary and/or a year long wall chart.

The Patient & the Carer need to get in the habit of checking them daily.

- From my many years as a Carer and from the many different people we have met, including cancer patients with other cancers, the majority have no idea what it feels to live with NETs, so don't try to empathise, just be there for them.
- For every appointment, (scan, test consultation), the Patient's Journal, and bring water & food for you both.
Each of you should also bring something to pass the time, I have waited 6 hours for a non-NET consultation. A book is best, you can switch off from everything around you.
- Discuss this with the Patient well beforehand. Introduce yourself to the medical professionals, as the Patient's Carer, (or the Patient introduces you).
The difference this seems to make, is that the medical professional takes note and allows the Carer to ask questions and get clarifications, on behalf of the Patient.

As I mentioned, discuss this with the Patient well beforehand. Do Not force this idea on the Patient, he/she must be comfortable allowing it.

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E O'L October 2021

Liz's story

I was just diagnosed in June 2021. I am very happy to share my experience to date if it helps somebody else.

My NETS tumour presented itself as a small lump in the middle of my back last Oct 2020. I wasn't in any pain; I couldn't really see it and could barely feel it. I went to my GP in Dec. She said she wasn't too concerned but suggested I got an ultrasound to be sure. I got the ultrasound in March, and it said to be on the safe side, to get a biopsy done or have it removed. I was referred to the Beacon and we decided to have it removed to be 100% sure. The result back was that it was a neuroendocrine tumour, I couldn't believe it as I was feeling so well. The only other symptoms I had, which we didn't relate, was that in March I felt nauseous, tired, lost weight and had a bad cough. I was given inhalers from my GP for the cough and something to settle my stomach.

Following the diagnosis in June I was referred to St Vincent's. I went for a ct scan, which showed the primary tumour is in my lung and the others are in my bones, liver, and also the disease is at the site of the lump in my back. In July, I went for a PET scan which unfortunately showed a tumour on my brain, I was devastated and I'm still very concerned.

In Sept I had three radiotherapy sessions on my brain.

In August I started Lanreotide injection and Zometa bone infusions which I get every 28 days.

When I was told I'm suitable for PRRT in Uppsala, I took as a very good option to have. My first trip there was this month in October.

My life, like everybody's else in this situation, changed overnight. The hardest thing I've ever had to do was to tell my two children who live abroad. My son, his wife and their two little girls are arriving home from Sydney next week for three months. I've never met my 2nd granddaughter and it is certainly keeping me going. My daughter lives in Edinburgh and thank goodness has been able to travel over a few times so far to see me.

I took very good advice from a friend who said to take each appointment, scan and treatment as it comes and try not think beyond it as it's too overwhelming.

I also try to remain strong and positive. The unknown before the treatment plan was difficult but I look on getting the treatment now as a positive thing. I also

feel I'm in capable hands with the doctors and nurses who are looking after me. I always bring a family member to an appointment to make sure I don't miss anything. The doctor allowed my daughter listen in on the phone at an appointment which really helped her know what was happening.

I write everything down and keep a diary to refer to.

The oncology nurses in St Vincent's have been so helpful and supportive to me. Tommie Gorman, through the contact of a friend, kindly rang me which I really appreciated, as I knew nobody else with NETS. He put me in contact with Tom O'Donoghue and I had a good chat with him about Uppsala.

Overall, I'm doing ok, I'm just recovering from the PRRT treatment which I received on 18th Oct. I felt very nauseous and tired for days but feel I've turned the corner now, at last.

ES October 2021

Charlie's story

I first got a severe pain back in 2016 August just under my rib cage on my right hand side and it was like someone driving a knife into me. I was driving at the time when I got home, I had to crawl out of the car my wife rang the gp who said come down. He saw me and said symptoms were gallstones and sent me for a ultrasound which in fairness was the next day. I had the scan and the following day my gp requested that I call in on my way home from work I did and when he entered the room my wife was with him which was a shock so I knew it was a bit more serious than gallstones he said they had found a large tumour in my pancreas and it was cancer- you could have knocked me down with a feather-a massive shock-I didn't know what it is like to be hit by a train but I think I do now.

I felt numb and very empty we went home after the gp had organised me to see someone in the mater for scan and biopsy. We arrived home and sat in the car totally shocked for ages then we had to tell our kids which was a nightmare. It is very important to keep busy if you can and keep your mind in a good place because it is a long and difficult road but if you keep positive you will get there. Whatever people do when diagnosed please keep a diary because when you go for appointments the people you see may not have information or dates right so at least you can steer them.

Anyway, after many biopsies later and still thinking I had pancreatic and liver cancer of the most aggressive type it was a huge relief to find out it was nets it is much less aggressive in my case and I had options

It was sept 2017 when I had my op in St Vincents and thanks to the professionals there I am still here to relate my story.

In November 2018 I went to Uppsala for PRRT treatment and had 4 sessions there after which tumours did shrink slightly my point being once you have options make use of them they will extend your time here and hopefully give you a better quality of life.

I hope this is of some help to someone out there Adrian has my number if anyone wishes to ask me anything about my journey

CH October 2021