



A M M F

THE CHOLANGIOCARCINOMA CHARITY

Facebook Guest Posts and
Specialists' Comments

Cholangiocarcinoma Awareness Month

February 2014

www.ammf.org.uk

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Guest Posts

Enormous thanks go to everyone who was brave enough during Cholangiocarcinoma Awareness Month 2014 to take part in AMMF's Facebook Guest Post feature. What incredible stories of love and courage have been shared – from those currently undergoing treatment, those who have lost precious people to CC and, wonderfully, from survivors, too. It was heartwarming to see the kind and supportive comments coming in for those who have been 'lucky' enough to have benefited from surgery, especially as many times these comments were from those who had seen a loved one receive a late, wrong or missed diagnosis and all the devastating consequences of that...

These Guest Posts now appear here – collated in one special brochure. Photographs and external links have been included and are live in the download version*. Comments to the individual posts are not included although these, of course, remain on Facebook.

Specialists' Comments

AMMF received many supportive comments and CC updates from leading CC specialists and researchers for sharing with our supporters during Awareness Month. The ones that appeared on Facebook during the month are collated here also, together with their various external links*.

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* A small quantity of these brochures have also been printed, and are available on request. (Obviously, the links will only work when the download version is viewed online.)

CC DAY 1 – GUEST POST *from Tom Morement*

I have chosen Day 1 for my Guest Post as I consider the number one to be special.

It's special because it signifies going first and lighting the way – which is what my Dad did.

After he was diagnosed, it was his idea that led to the formation of a cholangiocarcinoma charity – and that light is now shining brightly.

The word cholangiocarcinoma is no longer one no one has ever heard of.

No longer are people left in the unknown as my Dad was.

Now there is a place where people can turn for support, help and information, AMMF.

So I dedicate this post and this day to my Dad, Alan Morement, who was and still is a light that burns brightly and leads the way.

Tom Morement
AMMF Trustee

*Dark is not opposite of light.
It is just the absence of light.
Similarly,
a problem is the absence of an idea.
Not absence of a solution.*



CC DAY 2 – GUEST POST *from Nikki Greenall*

I have written something for AMMF awareness month for the last few years as I am one, of the sadly growing number, of unlucky people who has lost someone to this disease. If you weren't lucky enough to meet Helen Smith then I'm afraid you missed out, because she was quite simply, fabulous. In previous years I have tried to explain what a warm, happy, shiny kind of person she was and I never seem to be able to do her justice! She tragically died at the age of 35 and genuinely was a person taken far too soon.

I think it is fair to say that Hel was not a great lover of exercise so I am sure that she has thoroughly enjoyed watching us in our AMMF fundraising activities. We started off initially taking part in the Race for Life – no mean feat for those of us that had not run voluntarily since the age of about 10! Last year, not only did we get the men involved, but the effort required escalated sharply. The group AMMF fundraising challenge was a gruelling 26 mile walk from Stonehenge to the stone circle in Avebury on a very warm summer's day. Be under no illusion, it was not a gentle stroll along a flat surface, we were scrambling up very large hills and fighting our way through stinging nettles at times! It was a great success with the entire group completing the marathon hike in very respectable times – all less than ten hours. There was a wide range of fitness levels in the group, (myself being in the 'least quickest' category) but the positive group energy, the determination to raise money and the beautiful countryside all helped to keep us hiking – even a group of sinister cows did not deter us.

I am pleased to report hot off the press, that the team (12 people so far but recruitment is on-going) have agreed that this year we will be taking part in a 'Monster Race' on the 1st November. It is a 5K course with 20 very wet and muddy obstacles along the way including barbed wire crawls, high walls, hay bale climbs and wading neck high through swamp water! I imagine there will be some rather amusing photo opportunities.

The goal as always will be to raise a good stack of cash for AMMF, a charity that needs everyone's love and support so we can help to raise awareness and hopefully find a way of successfully treating Cholangiocarcinoma.

We are doing it for all of the friends and families who have lost amazing people but particularly in remembrance of my best friend Helen Smith.



Photo: Helen Smith.

CC DAY 3 – GUEST POST *from Helen Tanner*

This is the third time that I have contributed an entry to the AMMF FB page during CC Awareness Month and this year I have decided to get on my soapbox!

As a CC survivor of more than 3 years now, I find myself a member of a very rare species. Great work is being done to improve the speed of diagnosis of CC so that surgery is more likely to be possible (much of this helped by funding from AMMF) – and we all know that this is the only chance of a cure. Also surgeons are developing techniques to tackle increasingly challenging cases.

It is after the surgery that things start to fall apart. Unless you have opted for being in something like the BILCAP trial, there is no recognised follow-up pathway for patients who have had a resection for CC. Unlike the more common cancers, where a clear 5-year follow-up programme exists, none of the doctors I have come into contact with have any concept of what might be appropriate and I have had to battle to get yearly scans at 2+ and 3+ years. After my next one in a few weeks, and all being well, I will be discharged and left to get on with it. With CC having such a high risk of recurrence, I feel I am being cut off from the possibility of early detection of problems which might be able to be treated.

I believe we now need to start campaigning for an agreed follow-up for CC patients after surgery – it's the next step on our journey!

Best wishes to you all, wherever you are in your own CC travels!

Helen



Photo: Helen with husband Colin on Braunton Burrows, overlooking Saunton beach – August 2013.

CC DAY 4 – GUEST POST *from Gavin Strachan*

In memory of my Dad, Ronald John Strachan (12.7.44 - 10.12.09)

My dad was diagnosed with cholangiocarcinoma in the late summer of 2008 and to say that the diagnosis came as a shock would be a huge understatement. To hear that it was inoperable from diagnosis and that it was a terminal disease felt like getting hit in the head with a cricket bat. Nothing can prepare you for hearing news like that and I know that, unfortunately, many of you reading this will know exactly how I felt. The sense of shock was unbelievable.

But we regrouped, talked and thought about every option and I told my dad that I would support him in whatever treatment he wanted to do or not do. Chemo or PDT were his choices back then and he chose the PDT over the chemo. His thinking and wishes were that he wanted the best quality of life possible for the time that he had left and he felt the PDT would give him that. I agreed and supported him all the way and looking back, quality of life with the PDT probably was better than what it would have been with the chemo. Plus it was a one shot treatment back then whereas chemo was ongoing and would have involved many hospital trips and everything that goes with chemo.

Life changed drastically after the diagnosis but we all adapted and got on with things as best as we could. What do you do? Adapt to your new normal or wallow around in misery thinking why me? Of course there was some soul searching and thinking of why me, but after a bit of that Dad got on with things as best as he could, as did I.

Dad fought a tough fight with a ton of bumps in the road. People say it is like a rollercoaster with many up's and down's, they've got that right. The good days are really good and the bad days, well I'm sure you all can relate to them as well. The end came in December of 2009 and my dad passed away peacefully in hospice.

Back in 2008 there were not many treatment options available to patients of CC. Thankfully now there are more and much better treatments out there. Much has been done over the last 5 years or so and more is on the horizon as well. We've come a long way in those 5 years with regards to research, treatment and raising awareness of CC but much more has to be done still. Much, much, much more in fact.

I would like to thank Helen and everyone else involved with AMMF for all of their outstanding work here and also the Cholangiocarcinoma Foundation in the US too. Both organisations are very dear to my heart and always will be. The fight goes on and we will get there.

Rest in Peace Dad.



Photo: Horse riding was something Dad learned to love after his diagnosis, and here he is in 2009, really happy after a session on Paddy at the riding centre!

CC DAY 5 – GUEST POST *from Julia Wise*

How do you recover from 3 years of being hit over the head, relentlessly, with bucketloads of bricks? How do you cope when you know you can never go back, but you don't know which way is forward?

My sister's cholangiocarcinoma diagnosis changed everything, for me as well as for her. During Sue's illness I was free-falling; when she died I hit the ground with a heart-shattering wallop.

My way of coping was totally unexpected. I started iPad drawing.

I have no wish to relive the past, but I can't turn my back on my CC experiences and simply walk away. It's part of who I am now and I will continue to fight this dreadful disease by spreading the word about CC and raising funds for AMMF.



Photo: Sue.

But how? I have two artificial knees, so I can't do a sponsored run, walk, climb or trek (that's my excuse, anyway) and I've been on so many diets over the years that my friends would die laughing if I even mentioned a sponsored slim, but I don't want to keep asking people for money without giving something back. So I wracked my brains to see what I had to offer in return...

Whilst I pondered this dilemma, I just kept on drawing – progressing from portraits of my family to portraits of my friends' pets.

Slowly, as I started receiving commissions, first from friends and then from strangers, it dawned on me that I'd found my fundraising/awareness niche... Pet Portraits. A friend built me a website as a donation to the cause and the rest, as they say, is DFP (digital finger painting) history.

So... do YOU know a pet in need of a portrait? Please visit <http://www.dfpportraits.co.uk> for details of how to get an original iPad drawing of your pet, in exchange for a donation to AMMF.

Please share the DFP website link and spread the DFP Portraits Facebook Page. Let's see how much awareness we can raise for this wretched disease so we can STOP it before more families suffer like ours have.

Thank you.

Julia

CC DAY 6 – GUEST POST *from Helen Morement*

I was thinking about Alan and what to write for my AMMF Guest Post today, his birthday, when out of the blue a word popped into my mind, Winston. This word arrived so clearly and firmly, I decided I couldn't ignore it, so here goes...

Alan had several major loves in his life – I like to think I was one, and our son Tom – but another of these was definitely Winston. Tall, grey, strong, full of character, and with just the suggestion of a military moustache – Winston was Alan's beloved horse.

Early in the 1980s Alan acquired Winston, a 7 yr old, powerful Irish hunter – not what he was looking for at the time, but a case of one look and love at first sight! And this partnership proved to be for life – Winston survived Alan by several years, finally leaving us for celestial pastures at the grand age of 30.



Photo: Alan and Winston.

Over their many years together this pair had numerous adventures and escapades, mostly with Winston in control, to Alan's despair. The memories are flooding back and are so clear...

Riding out in Epping Forest with a group of friends on a sharp winter's day en route to the Lost Ponds (a favourite expedition, although few of us could ever reliably find these ponds) – Alan heading up the posse when Winston decided to 'help out' and take us straight there. To be fair he had a way of knowing that destination, but it would have been more agreeable if he had stuck to the paths! So when I say 'straight there' that's exactly the route Winston took – the rest of us struggling behind through the brambles and under low branches, with Alan calling back to us, "Keep up, this is the direct route!" like he was in any sort of control! (I'll keep the 'going backwards over the jumps' at the hunter trials episode for another time...)

Over the years, at Christmas and birthdays a tradition evolved – Alan and Winston would celebrate together over a Guinness. (Well, Winston's was in his feed, he found the glass a bit tricky!) So I hope they're together today, just back from a hack through some glorious countryside and enjoying a celestial pint of the black stuff.

What's all this got to do with cholangiocarcinoma – nothing really, except to prove that this monster can't take away our happy memories, and they will always be there if we sit quietly and wait for them to come to us...

For you, Alan, on your birthday, happy memories and the inimitable Leonard Cohen with, "Ain't no cure for love..." (You speak to the heart, Mr Cohen.) xxx



"Ain't no cure for love..."
Leonard Cohen

CC DAY 7 – GUEST POST *from Sharon Solomon*

Another year has gone by and I am still battling my way through this terrible disease, having been originally diagnosed in 2011. I have now got to the stage where after my first round of chemo I was told in September 2013 that unfortunately there are now multiple pulmonary metastases in both lungs and also the pancreatic area and retroperitoneal area below the diaphragm. I was then given another round of chemo in October 2013 and in January 2014 was told that the chemo has stopped growth and there is no regrowth at the moment, but the chemo was affecting me terribly and they had to stop it for two months and do a blood transfusion. I am due to start my third round of chemo sometime in February.

I am not going to give up the fight, there are days when I feel really ill, I still have major nausea and the pain is incredibly tough to deal with most days especially as the cancer is basically all over my abdomen. On the 26th January 2014 my hubby Ronnie and I went to Malta on holiday for 8 days, as I really needed to get away from home and have a change of scenery. It was extremely difficult for me as we walked a lot and I still had days when I was very ill, but we did a coach tour of Gozo Island and a few days of touring around Malta itself and all I did was take “One Day at a Time” (which is why I decided to link to a video of this song – with pictures of our trip).



I am so blessed to constantly have the love and support that helps me get through each day from all my family and friends and I would like to thank each and every one of them for being there for me.

Thank you also to Helen and AMMF for all the love and support that they give each and every one of us.

CC DAY 8 – GUEST POST *from Claire Bradburn*

A year ago today, my life was turned upside down when I lost the greatest man I will ever know; my Dad.

Memories I have of my Dad are of him always fixing things. Even from being a child, whether it was a broken bicycle chain or roller skate, Dad was always there to fix it. As I look around my house now, I often smile fondly looking at the DIY my Dad has carried out, armed with his trusty tube of No Nails. That adhesive practically holds my house together! Funny how something can evoke such wonderful memories?

My Dad became ill in the summer of 2012. Rapid weight loss, no appetite, fatigue and abdominal pain were just a few of the symptoms. Constant, often weekly, visits to his GP as the pain was unbearable. These symptoms didn't seem to alert a cause for concern. Dad was prescribed a mass of weird and wonderful medications for excess acid, IBS, to name but a few. Even presenting at the local A&E got him nowhere. My Dad felt defeated.

Eventually, through sheer persistence, Dad was referred for procedures. Ultrasound, Sigmoidoscopy, Endoscopy – all came back clear.

December 2012, the week before Christmas and Dad developed Jaundice and was immediately admitted to hospital. CT scan followed and a diagnosis of Pancreatic Cancer with liver metastasis. It was only when Dad was transferred to another hospital six weeks later to see a Hepato-Pancreato-Biliary Specialist for palliative drainage of the bile that we got a diagnosis of Cholangiocarcinoma.

I will never ever forget that day. As I write this, my eyes burn with tears. A prognosis of 'probably a week' followed and my heart broke right there and then.

My Dad had spent all my life fixing things for me and this one thing I couldn't fix in return. Neither could he. Not even with superhero powers, in his little girl's eyes, and no amount of his trusty No Nails could either. I felt like a failure.

My Dad survived 9 days after diagnosis. He passed away peacefully at home with my Mum (whom he had been married to for 39 years), myself and my brother present. He fought to the end and for that I am and always will be incredibly proud.

I feel honoured to share my story with you as however painful it may be for me to tell, it can only emphasise how crucial it is to raise awareness. My Dad saw multiple GP's at his surgery and also Consultants at Outpatient appointments and it took six months of investigations to finally get a diagnosis. This is too long! Cholangiocarcinoma does not allow for slow process procedures, it is a ticking time bomb and time is of the essence here.

The work that Helen and all at AMMF do is tremendous. Their efforts ensure that those who have lost their battles with CC have not done so in vain. What a wonderful legacy that is? As well as funding research so one day, hopefully soon, the statistics of CC will prevail to be more curative than palliative. To all in our CC family, let's continue to fight so others are more fortunate than those we have loved and lost.

My Dad was a massive Queen fan and to end this tribute to him, on the first anniversary of his passing, I chose a favourite of mine that helps me remember my Dad and the enormous love and respect I still have for him, and always will:

*'Those were the days of our lives.
The bad things in life were so few,
Those days are all gone now but one thing's still true.
When I look and I find, I still love you. I still love you.'*



Photo: A lovely reminder of a wonderful childhood.

CC DAY 9 – GUEST POST *from Beryl Jones*

When I was diagnosed with cholangiocarcinoma six years ago, I was devastated. I couldn't find out anything about the disease or any support group to help me cope. I was convinced I had been given a death sentence.

I was told I needed an operation to remove a tumour from my liver – the thought of that was devastating in itself. I now know I was one of the lucky ones, because for so many people diagnosed with this disease surgery is not an option, their cancer is too far advanced.

My surgery was carried out at Aintree Hospital in Liverpool, by Mr Hassan Malik, whose kind and quiet persona belies how incredibly skilled a surgeon he is. I got through the surgery and although recovery was tough at times, eventually I recovered and can honestly say I have now returned to living my life to the full with my husband, Bill, my family and friends.



Photo: Beryl and Bill on holiday in Tenerife.

Just recently, Bill and I celebrated our Golden Wedding anniversary and we decided to ask our friends if, instead of giving us presents, they would donate to AMMF because we both felt the best present we could have would be to do something to help others overcome this devastating illness. We had an amazing response to this request – with an enormous number of donations and so many lovely messages coming in to our Justgiving page: <http://www.justgiving.com/Beryl-Jones2>

JustGiving™

Bill and I have just returned from a long holiday in Tenerife, soaking up the sunshine, enjoying the company of good friends and long walks along the cliffs taking in the stunning sea views. During the holiday, on 23 January, it was the 6th anniversary of the day I went to the operating theatre fearing the worst. Bill and I spent most of the day thinking how lucky I am to have survived CC, and thinking of others not so fortunate.

I will continue to raise CC awareness wherever I can, and if anyone feels knowing more about my CC experience would be helpful to them, you can find me on the 'Our CC Family' section of AMMF's website – I'm very happy to be contacted.

CC DAY 10 – GUEST POST *from Nicki Jackson*

Chris Jackson (8.5.56 - 24.6.12)

We met in a bar Sept 2003, he was 2 years younger than me, a toyboy!! We went out, had fun, fell in love, moved in together. In 2006 we got married, the second time around for both of us!! We had five children between us, a great family!!

We both worked hard, Chris had a business in London and I am a nurse but we played hard too and loved our concerts, theatre, restaurants and holidays!! The icing on the cake came in 2008 when we bought a little apartment in the south of France, we popped over as often as we could enjoying the scenery, sun and the vineyards. Life was good!!

Then, in late 2010, Chris had a health check, his liver function was high, too much red wine said the GP! Oh dear, nothing too serious we thought, just have to cut down. But Chris became more tired, an ultrasound scan showed nothing!! Then he turned yellow, alarm bells started ringing!! Chris was diagnosed in June 2011, the surgeons did their best, the chemo took its toll, Chris was so brave, but he died in June 2012.

Our lives have been turned upside down, never to be the same again. If only Chris was diagnosed sooner, the outcome may have been different so, as a family, we started fundraising. Stacey did the Race for Life, Matt the 3 Peaks Challenge, we held a fundraising day at home, Martin was so generous, Adam and I walked the Great Wall of China!! What an experience, so tough but we met many wonderful people along the way.

Chris also left a legacy in his Will for AMMF. Helen helped us so much and we are so grateful for all her support. So far we have raised over £11,500 and in Chris's name, this money will sponsor the 2nd of 3 annual grants AMMF is giving to the Institute of Hepatology, supporting their work into the molecular basis of CC. Research is the only way we are ever going to move forward, so I thank everyone who has sponsored us from the bottom of my heart !!



Photo: Chris and Nicki on their wedding day.

CC DAY 11 – GUEST POST *from Rebecca West*

It's been three years since our brilliant Helen died of cholangiocarcinoma, aged 35 years. She left behind a husband, beautiful daughter, loving family and gang of friends who thought she was truly wonderful.

I have walked in a fog of sadness for three years but recently I realised that Hel would want us to live and be happy; she loved laughter and fun and as our 40th birthdays approach I know she would say, 'Enough tears, get out there!' So I'm going to try.

Our group of friends have some good ideas to raise funds for AMMF in 2014 including a 'Monster Race' running through lots of mud! I hope it will raise funds and awareness about AMMF and the wonderful work they do trying to combat this awful disease.

For Helen...

*You can shed tears that she is gone, or you can smile
because she has lived.*

*You can close your eyes and pray that she will come back
or you can open your eyes and see all that she left.*

*Your heart can be empty because you can't see her or it can
be full of the love that you shared.*

*You can turn your back on tomorrow and live for yesterday
or you can be happy for tomorrow because of yesterday.*

*You can cry and close your mind, be empty and turn
your back, or you can do what she would want, smile,
open your eyes, love and move on.*

We love you always Hels ~ gone but never forgotten x



Photo: Rebecca (l) with Helen.

CC DAY 12 – GUEST POST *from Valerie Wrate*

On New Year's Eve 2013, I stood on the 12th floor roof of a hotel in Madeira with my husband to watch the fireworks – something I have always dreamed of doing. The excuse for booking the trip was our 50th wedding anniversary, but in reality we were celebrating something else. It was two years since my Whipple operation following a diagnosis of bile duct cancer, and I was feeling fit and healthy and almost back to my old self.

Following the diagnosis, I asked my wonderful Macmillan Nurse Lisa if this was the beginning of the end of my life as I knew it. In other words, was I going to be permanently sick? She replied that I was having a very serious operation and, although she gave me all the information I needed, I don't think my brain ever accepted what a life-threatening illness I had.

In December 2011, I underwent a six-hour operation at Queen's Medical Centre in Nottingham. Back home, I was cared for by my husband and family. I had delicious meals, served on a saucer as I could only eat a little at a time. At end of January 2012, I started a course of chemo at Boston's Pilgrim Hospital. Two weeks into the course, I renewed my ten-year passport. Seventy pounds thrown away? Oh no, to me a 10 year passport meant I had a future, and having a future gave me the necessary incentive to follow an exercise plan when I just wanted to sit in a chair all day.

I have heard people say that cancer changed their attitude to life, but I don't think this has happened to me. I realised how much people loved me, but I think that deep down, I knew that anyway. I became a Scrabble expert, playing against the computer when I could not sleep and dark thoughts threatened to creep in.

Just over two years on, I have now got back to the thing I most dreaded losing – my day-to-day ordinary life. My husband and I also have lots of holidays, abroad and in our caravan – and life is good!



Photo: Valerie and her husband.

CC DAY 13 – GUEST POST *from James Odell*

There are so many people who will have such happy memories and thoughts of you today, Dad. Birthdays are a time to celebrate and I know you'll be happy to hear that is what we are going to do. Everyone who loves you is so proud that we are able to post a message during CC Awareness Month, especially today – your birthday.

We know that since Dad's diagnosis back in 2012 he found AMMF and the work you do a real help. He made some good friends and really seemed to find something extra in being able to fundraise and to try and raise extra awareness by sharing updates and posts that other people affected by CC had contributed. He took great delight in watching the 'likes' go up on a daily basis and would encourage all his friends to take a look at the page. Dad, I think we would all agree that during the hardest time of your life – after being diagnosed with CC – the word that describes you best is, positive.

Dad always liked a laugh and to have fun, that became even more evident as he battled with this terrible illness. Even through the numerous hospital visits, tests and operations he always made the most of even the toughest situations and managed to make quite a few of the nurses laugh, too.

In the middle of his chemotherapy and, at the age of 60 he completed a 10K run in order to raise money and awareness on behalf of AMMF. He also enjoyed spending time with his two young grandchildren, and although we didn't know how much time he had, I know he considered himself lucky to be able to hold them and play. He was also determined to have a holiday in the sun, and it gives us great pride to be able to say, he made it.



Today would have been Dad's 61st birthday (he won't thank us for saying that) but what he will thank us for is for celebrating and enjoying it because that is what he would have done and that is what he would want.

Although Dad isn't around to read any of the wonderful posts left already this month, I know he'd be very proud to have been part of AMMF's CC Awareness Month.

Happy Birthday Dad, you are loved and missed by so many, every day.

Dad in May 2012 (just a month before his diagnosis).

CC DAY 14 – GUEST POST *from Margaret McRobert*

*“My grandad is fun and smiley,
My grandad is lovely and has a golden heart
My grandad is a cool dancing mate and makes me smile.
My grandad is like a hot chocolate on a freezing cold day
My grandad is the best of the best.
I’m the luckiest girl in the world.”*

(Written by 8 year old Laura, for Grandad, before he went into hospital in June 2011).



Photo: Derick at Montrose.

Twenty two months later, life for Laura – and the rest of the family – changed forever, when the ruthless CC robbed us of such a special “fun and smiley” husband, dad and grandad.

Diagnosed in June 2011, only six weeks after a clean bill of health at his annual Well-Man Clinic, Derick was scheduled for a Whipple, which, due to blood vessel involvement, was not possible. The removed bile duct revealed CC and the prognosis was six months, the CC having already spread to the lymph nodes. How could this be when, only days before, he had been tearing around the park with the grandchildren, the picture of health, totally unaware that CC had already silently and stealthily spread through his system?

Derick’s attitude from the start was 100% positive. CC might ravage his body but it was never going to destroy his spirit and, for fourteen months after discharge, we had our “cool dancing mate” grandad back, relishing every minute, enjoying the many milestones in the lives of our 7 grandchildren. His health was excellent, so much so that, after two clear scans, the consultant admitted that, had he not read the histopathology report, he would have doubted the CC diagnosis. One year had passed – he was one of the 5%. We were ecstatic!

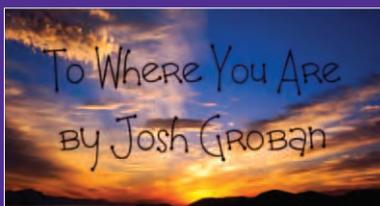
Our ecstasy was short-lived, however, as, by September 2012, the insidious CC, which had been lurking unseen, had spread to his duodenum, necessitating a bypass op. This was a blow after the clear scans but he was soon home proudly boasting of his weight gain and he amazingly then enjoyed another 7 months of good health. On April 21st 2013, however, with no warning, after a beach walk in the morning, he was online, renewing his tax disc for a year (ever the optimist!) when he complained of blurry vision. G Docs were called, tests done, results all good. Three hours later, however, he had a diabetic seizure (he was not a diabetic) and then another, after which he never regained consciousness. The ruthless CC had spread to the pancreas and done its worst.

CC has robbed us of “the best of the best”, a devoted and much loved husband and dad and an adored grandad. Derick was everything to all of us and we miss him so very much – his smile, his optimism, his humour, his music, his hugs and, most of all, his love. But... given that, after a six month prognosis, he had 22 months of amazingly good health (and sadly others are not so fortunate), what if there had been tests that could have alerted doctors early to his CC at his annual Well-Man clinics?

An earlier diagnosis, making surgery possible and he might still be with us – oh, if only! How good it is to hear, through AMMF, of CC survivors who were diagnosed early with successful outcomes.

Thanks to Helen, AMMF and its countless fundraisers and supporters, this dream of early diagnosis will one day become a reality. Guest Spots show clearly that CC has a knack of afflicting special people. The battle with CC for many of our special loved ones, like Derick, is over – in their memory, however, we must ensure the fight goes on!

On Valentine’s Day, I attach the track, “To where you are” by Josh Groban – for those of us who, today especially, are feeling the painful loss of a “forever love”.



“To where you are”
by Josh Groban

CC DAY 15 – GUEST POST *from Malcolm Robinson*

The 15th February 2010 was the day I realised that the medical reality for those like me with a CC diagnosis is that only 5% will survive for one year...

AMMF has been around for me since then and the current developments are proof, if it were needed, that we have some real momentum and direction.

Awareness raising with GP's is a great idea – I handed my letter in personally with a 'thank you – keep up the good work' note written at the top. But then came the Newsletter* and the piece next to Helen's smiling face, 'A Symbol of Hope...'. That, put simply, is what sums up AMMF to me and I trust to others too.

When a batch of the new pins arrived I was more than impressed. I bought a t-shirt** too – you never know, there may be a half marathon left in me yet!

I will wear our pin often and use it to raise awareness whenever I can. It will be a conversation opener on many occasions, it will travel with me to the US and Europe on holiday, I will hand one over to my MP (bit of political awareness raising), and when I contribute to other charities it will enable me to share the journey that the AMMF CC Family is undertaking. The words and music of Craig and Charlie Reid – The Proclaimers – in their song 'Love Can Move Mountains' ought to accompany us!



But most of all I think I am looking forward to the time when someone taps me on the shoulder and says, "That pin you're wearing... tell me your story... I have one too". As you can see, I've started already with my new five week old grandson, Louis. When he holds his new grandson in his arms who knows where the journey will have taken us?

Photo: Malcolm and Louis, wearing that symbol of hope.

* For those who may not have seen AMMF's newsletter:

<http://www.ammf.org.uk/2014/02/04/ammfs-newsletter-just-out/>

** <http://www.ammf.org.uk/ammf-shop/>



"Love Can Move Mountains"
by The Proclaimers

A cynical mind
Won't help you through the night
And it can't hold you up
When you're too tired to fight

Where you didn't have the strength
To look after yourself
You find all that you need
For somebody else

But love can move mountains...

That impossible task
You're thinking of
Is one you can complete
When you're driven by love

And the strength that you find
Won't go slipping away
Once it enters your soul
It's reborn every day

Love can move mountains...

So if you're lucky enough to live
To see love come your way
Be thankful every day
That it stays
Oh that it stays

A cynical mind
Won't help you through the night
And it can't hold you up
When you're too tired to fight

But love can move mountains...

CC DAY 16 – GUEST POST *from Diane Peternel*

Our experience with cholangiocarcinoma is short but most definitely not sweet. As everyone involved with AMMF is aware, this disease is all too often diagnosed far too late for treatment to be successful. In our case we didn't even get chance to discuss treatment, our entire experience lasted just 5 incredibly difficult days from diagnosis.

There isn't a day that goes by that we don't think of Mum, whether it's the wonderful family memories that she gave us all or when a situation arises that takes us back to that sad time.

I chose to be a guest poster this year for the first time after hearing about the new GP awareness scheme from Helen at AMMF. I've had several occasions at the doctors over the years since losing Mum where, for whatever reason, we find ourselves discussing what happened with Mum. When I say the word cholangiocarcinoma the doctor invariably says something along the lines of, 'Are you sure?' Or raises their eyebrows and says, 'Really?' One even said, 'I don't think that's right, that's very rare.'

So to find out from AMMF that the second most common form of liver cancer in the world is so often missed (because the symptoms are indicative of other illnesses that doctors don't think of it) that only 5% will survive one year from diagnosis, makes me both sad and angry at the same time. Then when you hear that the 95% who succumb to it totals approximately 1800 people in the UK alone each year it becomes obviously imperative that we do all we can to raise awareness. We will be doing all we can to increase awareness.



Photo: Team Jean at last year's Race for Life – Diane (r), sister Jayne and two nieces Corinne and Frankie.

CC DAY 17 – GUEST POST *from Sandie Gapper*

We don't usually comment before a Guest Post, but many of you will remember Sandie's exuberant post last year, and will know she is a girl with an amazing amount of courage. Her post this year is quite different – when you read it you will admire her courage all the more, as she uses her very personal reasons to encourage awareness raising on behalf of others.

Cholangiocarcinoma... is one evil disease. When it strikes, it has no respect for age, colour, creed or sex. There are few symptoms and those that do appear are often misdiagnosed due to lack of GP and hospital awareness of this disease.

Does YOUR doctor, nurse or local hospital know about it?

It causes 1,800 deaths per year in the UK, only 5% of patients will survive one year from diagnosis, and the incidence is rising. The treatment and their effects are harsh and invariably only give time... not a cure. There is only one cure, surgery, but the recurrence rate is frighteningly high. Early detection through awareness is vital.

Please help – pass the word and create awareness. Please Share and/or Like this post and spread the message as far as possible.

Why I am asking you to do this?

Cholangiocarcinoma struck me two years ago, I was lucky, I had that life saving surgery, but it has returned and I am now in a palliative care programme.

Please raise awareness... maybe your actions will save a life.

Sandie xxxx

To see Sandie's 2013 Guest Post, follow the link (it's on Day 26)

<http://www.ammf.org.uk/2013/03/07/your-inspirational-guest-posts>



Photo: Sandie.

CC DAY 18 – GUEST POST *from Liz Heywood*

My Dad's journey with Cholangiocarcinoma – John Smith.

As I read through all the amazing, inspirational, sad, moving and reflective posts again this year, I realise another year has passed without my wonderful Dad.

Bank Holiday Monday 4 May 2009 is a date I will never forget, but for all the wrong reasons. Because that is the day my precious Dad rang me from his home in Florida to tell us he had been diagnosed with CC and had been given around 12 months to live...

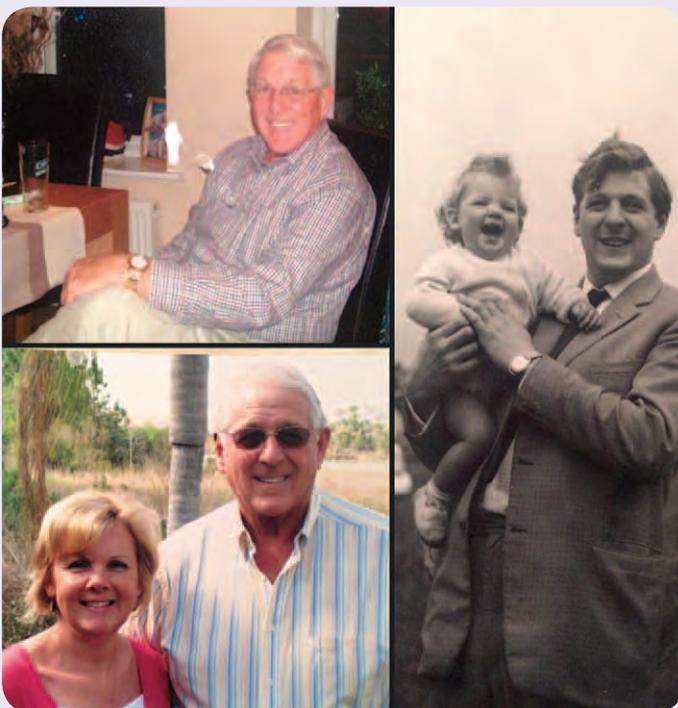
Twelve months to live? "But you aren't ill, Dad" I said through my tears, and he hadn't been. No classic signs of weight loss, jaundice, itching or pain, just raised blood tests detected at a routine cardiac follow up, years after having a heart bypass and pacemaker fitted.

As an experienced paediatric nurse, cholangiocarcinoma meant nothing to me. I guess I was in denial, but have to admit to a quick google search, the findings from which, as we all know, were bleak. But, I reasoned, my Dad was being treated in America, surely if anyone could save his life they could...?

What followed was a roller coaster, because a mere 24 hours later, after I had made plans to go over to the States and spend time with my Mum and Dad, I received another phone call to say the surgeon had called back and was now willing to offer surgery which could potentially save my Dad's life. Without a second thought, my Dad had total faith in his surgeon...

Two days later I was with them, as the journey towards surgery began. The whole preparation procedure took five weeks, with a lot of difficult times for Dad. I went back home to my family and work whilst this was going on, and returned to Florida to be with my Dad as he faced what is the most major surgery a person can face, a liver resection...

The day before his surgery is a day I will treasure forever, enjoying time together doing normal 'stuff' before my Dad drove himself the 100 miles to the hospital, at his insistence I must add!



Sadly, Dad's surgery didn't go as we hoped and after a stormy 9 days my Dad passed away in peace and dignity with my Mum, brother and myself at his side. A mere 7 weeks from the day he was diagnosed...

Unfortunately, it wasn't until I was back in England some weeks later that I discovered AMMF and the wonderful Helen and her team. Since then we have continued to raise money through my Justgiving site and I have had the pleasure of meeting with Helen, representing AMMF at the Christie Hospital in Manchester with Professor Valle.

Through AMMF I have also made some friends who share our common aim to continue to raise the awareness of CC.

I realise my Dad's story didn't have the ending we all prayed for but hope, with earlier detection and continued research and awareness raising, the journey for others may have a different outcome.

Love you Dad xxxx

CC DAY 19 – GUEST POST *from Andrea Fear*

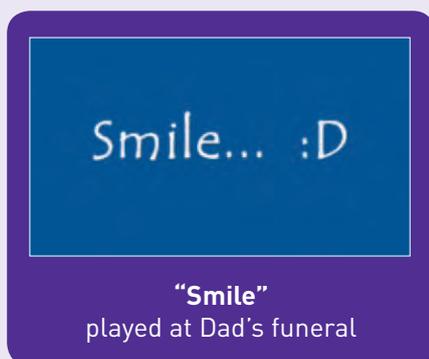
*In Memory of my Dad – John “Mac” Clark
(11.12.47 - 19.02.11)*

Three years ago today we said goodbye to a very special man, my Dad, who sadly lost his life to cholangiocarcinoma.

Twelve months previously I had never heard of cholangiocarcinoma, and neither had any of my family or friends. Dad became jaundiced in February 2010 and doctors at first thought it may be hepatitis or gallstones. Eight weeks after his first doctor’s visit, many blood tests, ultrasound scans, CT scans and a failed ERCP, CC was diagnosed and our world was turned upside down. The rollercoaster ride began!

During this time I discovered the internet site **www.cholangiocarcinoma.org** The people on this site became a great comfort in what I can only describe as the worst and scariest time of my life. They knew how I was feeling as they had been or were going through the CC rollercoaster ride too. Many friends were made (my CC family) and I was introduced to AMMF and the wonderful Helen. Dad’s CC was inoperable, chemotherapy was planned but, despite numerous stent operations, Dad’s bilirubin level never came down low enough to start treatment. In September 2010 we were told nothing else could be done, just over 4 months later Dad passed away peacefully at home in the arms of Mom and I.

In Dad’s memory we decided to raise money for AMMF, hoping to help other families going through this terrible disease. Thanks to family, friends and Dad’s work friends holding the Christmas raffle in his memory, we have currently managed to raise over £4,700, not bad saying the target was £500. I know that if Dad was still here he would be overwhelmed by this. I really don’t believe he knew how special he was to so many people.



Not a day goes by without Dad being in my thoughts, I miss him more than words can say. Gradually over the last year the happy memories have started to replace the “CC” memories and when I close my eyes I now see “my” Dad, something that for so long I worried I’d never visualise again.

One of the things I loved and admired about my Dad was his ability to keep smiling, no matter how tough things got, what bad news we were dealt, the smile never faded. He was a one in a million Dad and I’m glad he was mine.

To the world he was one, to us he was the world. xx



Photo: Dad with my son Jamie. Memories are a wonderful thing, and Jamie has lots that he still loves to share.

CC DAY 20 – GUEST POST *from Marcella Smith*

In memory of Stewart Smith – My Husband (14.05.56 - 05.09.11)

One fine Saturday evening in July 2010 we went out with our friends, walking into town to have a meal, walking back laughing and joking. On Sunday we were recalling the events of the previous evening, not envying one friend who had a Sunday lunch to prepare for her family as she had just one glass of wine too many. On Monday, Stewart presented with unbearable itching and jaundice. Our lives were never the same again and little did I know that our night out would be the last ‘normal’ night out we would ever have.

When we were advised that Stewart had CC, we were not told for some considerable time that it was operable. When we heard that it was operable we were relieved, but unfortunately the outcome of that operation was devastating. Not only had they not been able to remove all the cancer, he developed a portal vein embolism. With the enormity of the surgery and the embolism, unfortunately the time from then on until his death was traumatic. He was too ill for chemotherapy and it pains me to say that he did suffer both physically and emotionally.

Cholangiocarcinoma is ruthless and it has devastating effects. My wish is for earlier diagnosis and better treatment. So many different cancers have progressed and this is my wish for CC. Through AMMF this can be achieved for others and is what we must all strive for.

Yes, CC is rare although it is on the increase, and yes if I read about someone having a rare illness, I can shamefully say that I would probably think ‘it won’t happen to us’. We were a normal happy, healthy family and everyone must believe that CC can strike at any time and it can happen to them and so research into CC is vital.

I miss Stewart every single day. My memories of our 28 years of marriage are very happy, but my heart aches.



Photo: Stewart in London on our 25th wedding anniversary.

CC DAY 21 – GUEST POST *from Ali White (Mrs Johnny Ferguson)*

In memory of Johnny Ferguson (21.02.63 - 17.04.13)

I've been following the AMMF Guest Posts on Facebook this February; heartened to read about the people who have survived CC; sharing the heartbreak of those who have lost the people they love.

As the day for my Guest Post drew closer, I found myself feeling unsure about taking part.

Johnny Ferguson was deep down a very private person, and he avoided talking about his illness unless he absolutely had to. So I'm not going to write about his CC experience. It's too soon. Too raw.

Instead, I'm going to call on one of Johnny's myriad talents – one that lives on, and keeps me keeping on every day: his genius for making friends and connections, everywhere.

So if you're one of those people whose life was made better, funnier, more interesting, more vivid, by knowing Johnny – read up on the information on this dedicated site (<http://www.ammf.org.uk>). And spread awareness – especially here in Ireland, where even fewer people have even heard of it. Cholangiocarcinoma is a formidable adversary. Its incidence is increasing, but no one knows why. More research is vital.

Johnny lives on in the hearts of all of us who loved him. He was truly, the brightest feather in our wing. Today would be his 51st birthday. He would love to be here.

Happy birthday, Johnny Ferguson.



Photo: Johnny Ferguson.

CC DAY 22 – GUEST POST *from Gemma George*

This time two years ago I was slowly learning about cholangiocarcinoma and coming to terms with the fact that this terrible disease was silently and rapidly infiltrating the body of my beautiful sister, Lisa. Two years on, I'm mourning her death and am still horrified by the often symptomless and devastating nature of this illness.

It all started with a trip to the doctor's. Lisa had a slightly uncomfortable feeling at the one side of the top of her stomach. She wasn't worried, but thought that she had better get it checked out. She didn't think for one moment that the appointment would be the starting point of a chain of events that would result in a terminal diagnosis.

Once we knew what we were dealing with, we knew that the prognosis was bleak. For me and the rest of our family it was an horrific time, I can't even begin to imagine what it must have been like for Lisa. She was amazing though, she did not want to know timescales and she did everything she could to survive. I researched extensively in the hope of finding something, anything, that would keep my big sister alive.

When we realised that conventional medicine could only do so much, we changed her diet, limited her exposure to chemicals and embarked on a positive thinking mindset. We were prepared to try anything to make her better. Whilst ultimately none of these things saved her life, I truly believe it helped Lisa's mental wellbeing as it gave her something to focus on and it enabled her to gain an element of control.

In July last year we travelled to The Christie hospital in Manchester in the hope that Lisa would be able to receive a treatment called Selective Internal Radiation Therapy (SIRT). Unfortunately, it was too late. Less than two weeks later my precious sister was gone. She died from septicaemia 10 days after receiving chemotherapy. Her body was simply too weak to cope with it. She was 43.

Lisa has left a massive hole in all of our lives, particularly her son Riaz's who turned 13 the week before she died. I often momentarily and blissfully forget that she's gone. The realisation that inevitably follows seconds later is like a punch to the stomach, and 7 months on that punch is still as harsh and breathtaking as it was immediately after her death.

But I am here, I am alive and I know that Lisa would want nothing more than for us all to be happy. I endeavour daily to adopt the positive outlook that Lisa and I embarked on and I am definitely a happier person for it. I try to see the best in situations and I try to appreciate all of the good in my life, however small. I have Lisa to thank for that.

In September last year my friend organised a school charity bike ride in memory of Lisa (Lisa was a teacher) and half of the proceeds were donated to AMMF. We are already planning the next fundraiser – a karaoke night in March as Lisa loved to sing and it would be her birthday weekend.

AMMF is a wonderful charity and the work that they do to raise awareness of this devastating disease is priceless. I am thankful that I found them and that I can do something to help this deserving charity.



Photo: Me with my sisters Lisa (r) and Helen on my wedding day.

CC DAY 23 – GUEST POST *from Nic Othmani*

Take My Hand...

I believe a grief journey of healing is an intensely unique and different experience for each person, one where everyone grieves in their own way and in their own time. I wanted to share some comfort and give hope to others from having lost a loved one, for me it was my wonderful Dad almost 3 years ago now.

I remember being told, just after we lost Dad that the word bereaved literally means “torn apart”. I knew that my life was to change forever and at that moment I began to realise exactly how much.

I was always a ‘Daddy’s girl’ but having been single for a decade I also spent lots of my time with my Dad, times full of chats and laughter, he really was my best friend and just so much fun. Ten years is a long time and it was a really special relationship that we shared. You never get over losing something as precious as that.

It was now time to learn some coping mechanisms, which 6 weeks personal therapy with a supportive counsellor helped teach me and, whilst a piece of me died inside with Dad, I had my whole life ahead of me and had just become a mum and a wife. Celebrating Dad’s life and talking about him has helped keep his memory alive. Memories are something that cannot be taken from you. I am lucky to have an incredibly tight support network and feel blessed to have these very special people in my life. I can’t thank them enough. They all know who they are. I firmly believe the quality and quantity of understanding support you get on your grief journey has a major influence on your capacity to heal. It’s not something you can do alone.

To be truly helpful and supportive the people in your support system need to appreciate the impact the death has had on you. I have had the most amazing guidance from people who love me and have walked with me, they helped me get my ‘blondie bubbles’ and smile back, and I love them all so very much. They were all of the same way of thinking, “Take my hand Nic and I will walk with you, but I will never pretend to have walked a mile in your shoes”. I learnt so much from them all and always remember that poignant saying.

I confronted the reality that I was going to lose my Dad many months before he died. Not because I wanted to give up but once you hear the words “terminal” you have to have some degree of acceptance. A close friend of mine said, “Why don’t you tell your Dad every single thing you want to say to him before he dies” and I did just that. It was fondly named the ‘garden chat’. It felt so uplifting to tell someone how much you love and adore them and to thank them, too. I will never forget that time and it played such a large part in my grief journey. We should all spend more time in life telling people how much we love them and feel about them. I realised the other day I have been able to talk about my Dad for over a year now without crying, which I know means I am healing and dealing. I have Dad to thank for his cheerful approach to life and remembering his words to be happy and not waste a second of life as it really is so short. Those words have such an impact from someone who “really” knows.



Photo: The word montage below represents many of the words that are in my mind when I think of Dad and always make me smile remembering him 😊

Dad and I also used the saying to each other of “the new normal” regularly. Every step of Dad’s journey had an impact on both him and others and we learnt to adjust to how life was going to be each step of the way, one step at a time. It has really helped manage painful times on my journey through life and one that I use now whenever I need to draw strength. Thanks Dad.

Dad always wanted me to keep smiling and have lovely plans for the future and to allow myself to be happy when he had gone. Whilst I wish he was going to be on the Tunisian Sands with us this year in my husband’s home country, I know he will be around us. Last year on holiday there was a butterfly that hovered over my Mum’s head for about 15 mins. I look forward to this year’s sign whilst we toast my husband a Happy 40th birthday and raise another glass for my lovely Dad. You really were one in an absolute million and I see you everyday in my beautiful girls’ smiles – love and miss you always Dad, you will always be part of my life.

I wish you all courage and strength to find comfort, peace and hope.

Love Nic x.x.x.x.

CC DAY 24 – GUEST POST *from Stewart Arty Ibbotson*

Just over 3 years ago I was diagnosed with cholangiocarcinoma. Mine was one of the less ‘usual’ versions of CC – Ampulla of Vater or cancer of the pancreatic part of the joint bile duct.

From diagnosis to Whipple operation was only two weeks and this was over the Christmas and New Year period 2010/2011. The swift and decisive decisions made by the consultants at both Scarborough and at Castle Hill where the operation was carried out, are the reasons I am still around to raise awareness about this most difficult to diagnose cancer.

I support AMMF’s GP Awareness Campaign – GPs must be more aware, especially of “Obstructive Jaundice”, to enable more people to beat this disease.



Photo: Stewart with his consultant, and sporting a Whipple Warrior t-shirt!

(For the FB group, Whipple Warriors in the UK, go to: <https://www.facebook.com/groups/508517525927691>)

CC DAY 25 – GUEST POST *from Sonya Dixon*

My dad died three months ago today. It still seems unbelievable, it all happened so quickly. He was well until September when we all thought he had a tummy bug... and then the GP suspected Irritable Bowel Disease. In mid October after lots of tests and scans, shockingly, he was diagnosed with cancer and it then took another three weeks for the accurate diagnosis of bile duct cancer to be given... cholangiocarcinoma.

We all thought, trust dad to get a cancer that no-one's ever heard of, but then we started reading the stats. Only 5% of those diagnosed with cholangiocarcinoma live a year from diagnosis. They are typically the 'lucky' ones for whom diagnosis comes early enough for surgery – the only cure for this horrible disease. But the fact is, for most, diagnosis doesn't come early enough, and it didn't for Dad. Three weeks after his diagnosis he died.

I'm writing this as part of a drive by the AMMF [the cholangiocarcinoma charity] to increase awareness of this disease – amongst everyone, but particularly amongst GPs. Raised awareness amongst GPs may mean that someone, somewhere, who presents with seemingly innocuous symptoms may be diagnosed sooner, because their GP knows about bile duct cancer. Along with many other people whose lives have been affected by the disease, I'm going to give my GP Practice a letter about it. Whilst many of you – my friends here on Facebook – will have not even have heard of cholangiocarcinoma, I would be so happy if you too would download the letter and give it to your GP Practice. You can get from <http://www.ammf.org.uk/cc-awareness-month-february-2014>

My dad was real character. He was a very funny man, super quick-witted, the life and soul of the party and not always terribly bothered about being appropriate. A bit of an unconventional dad. He was also Pops to my niece Lily, and to my little boy Archie, born in 2012, for whom the white beard was a source of constant fascination and the belly a very comfortable spot for a nap, accompanied by Pops singing all the old music hall tunes he sang to us as children.

It makes me terribly sad that Archie won't remember him. How wonderful if I could help to make it different for some other little boy and his granddad.



Photo: Pops and Archie, June 2013.

CC DAY 26 – GUEST POST *from Kirsty Mackay*

This time last year we had just discovered AMMF as our sister Nikki (41) had been diagnosed in October 2012 with cholangiocarcinoma (CC). Nikki wasn't just our sister, she was a wife, a mum and a daughter and she died on 17 March 2013, 5 short months after being diagnosed. Words cannot describe how much we miss her and the family dynamic is all wrong.



Photo: Nikki.

Within 3 weeks of her first symptoms of stomach pain and jaundice, she had a diagnosis of CC much to the astonishment of her doctor, and from that point on she and her doctor fought to beat it. Every brick wall her doctor came up upon he found a way round it. Nikki's attitude was that if there ever was a glimmer of hope, to grab it and she kept on surprising us with her strength and courage. Her strength against the disease and the multitude of risky medical procedures she was prepared endure (endoscopies, stents, external bile drain, portal vein embolisation, an aborted resection, gastric bypass, liver abscess, liver drain) all to try and see her daughter's 4th birthday and her son turn 18. Not once in the 5 months did Nikki complain, challenge or ask why her, and she was so very dignified, accepting and positive until the very end.

CC is a monster of a disease and it throws curve balls that send the best of doctors off track. As we read the posts last year we knew that in 2014 we would be one of those families to have lost someone to this disease. Hope had been exhausted for Nikki, but we believe that there is hope for others and that one day, thanks to AMMF, the survival rates will be better and earlier diagnosis will be a reality not a dream. We know not every story is the same as ours and we are always delighted to read about those who have survived it. Even when Nikki knew she would not survive she asked that her doctors take every scrap of knowledge they could from her case and use it for the greater good. We hope that from every loss, something new is learnt about CC and we believe that with the passage of time these personal stories will become dominated by tales of survival and not loss.

Helen has been a huge support for us since Nikki's death and it would be easy to forget that she has been to that dark place where too many of us have been. Without Helen, the research and the drive to put CC on the medical map wouldn't be where it is today.

Thank you for reading Nikki's story, and we will leave you with one of her favourite songs that she had requested to be played at her funeral:



"I'm in the mood for dancing..."
The Nolans

CC DAY 27 – GUEST POST *from Jessica McMullen*

So this is my 3rd post for AMMF's CC Awareness Month, which means another birthday of mine (21st Feb) without my Mum, Tina, another wedding anniversary for my Dad (26th Feb) without his wife, and another birthday my Mum is never going to see – today, 27th February.

February is a very important month for me. It brings back a lot of happy memories but every year now, even though I want to remember Mum on her birthday, I dread writing this post. I should be writing a birthday card, 'To a wonderful Mum...' not this post, not me, not now, CC... what the hell is that?

So many mixed emotions, because I love to be able to remember my Mum in this special way, and I have felt more inspired than ever by all the posts shared so far this month. But writing this post means I have to remember the pain and it still hurts. I miss her every day, but writing these words makes it even more real and it reopens those wounds as if they are fresh. I'm sure you know the feeling.

This year has been different however. I have made progress; my wounds are slowly changing to scars. I may never be the same again, but I am rebuilding a life after my loss and using my Mum's strength and love to guide me. I have a lot in my life to be thankful for and the fog of anger, hatred and resentment has begun to lift enough for me to realise that again.

I too want to talk about the journey of grief and share a message of comfort and hope this February (similar to the brilliant post written by Nic Othmani on Day 23). This time last year I was in a very different place, but I now know what she means. You have to get there in your own way and your own time, so my message this year is that things can change and that the darkness does not last forever.



"Yes Sir I Can Boogie"
Baccara

[one of my Mum's 'mad half hour' songs – especially good for singing into the hairbrush!]



Photo: Mum on her wedding day, 26 February, 1983.

With some help I can now remember again the warmth and love that my Mum left behind and, even though I was unsure at first, I am glad I found some support. There are lots of free services out there which can help and I would like to take this opportunity to recommend and thank my local Treetops Hospice for helping me. <http://www.treetopshospice.org.uk/our-services/adult-bereavement-support/>

Happy Birthday Mummy, I will have a boogie for you!

CC DAY 28 – GUEST POST *from Gillian Corrigan*

Although I have worked in healthcare since 1980, it took until 1997 for me to hear the word cholangiocarcinoma, and even then it was through personal and not professional experience (Alan Morement was my brother-in-law).

I don't live in the UK so do my awareness raising on foreign soil, but nationality is irrelevant in our quest.

In this month's Guest Posts, there have been so many instances of medics not realising the importance of those all too often vague symptoms of cholangiocarcinoma, leading to late diagnosis and its devastating result, that I wanted to share a recent heartening experience (apt word as I work in cardiac care!):

During the course of a work up for chest pain and respiratory issues, my patient's doctor noted some liver abnormalities and immediately ordered further tests and an oncology consult to rule out various things including cholangiocarcinoma. It was so good to see CC being a first line thought – particularly from a non-specialist doctor.

And especially impressive as this happened during Cholangiocarcinoma Awareness Month!



Photo: Awareness being raised in the US by Julie, Ken and Gillian.

Cholangiocarcinoma Awareness Month – February 2014 Specialists' Comments

AMMF received many supportive comments and CC updates from leading CC specialists and researchers to be shared with our supporters during Awareness Month. Here are the ones that appeared on Facebook:



*Professor
Brian Davidson*

From Professor Brian Davidson

Delighted to lend support to the AMMF and the work of the cholangiocarcinoma charity. Congratulations first of all for such an easily accessible and readable website. There's lots to access from patient information, support for friends and relatives and information about developments in both surgery and oncology. Always great to hear from other centres developing specialist interests and support groups.

2014 should be a good year for research and clinical developments with new studies on novel biomarkers for the earlier diagnosis and new targeted therapies for treatment which we hope will be more effective and with lower toxicity.

Let's hope that together we can make a major impact on the disease this year.

Brian R Davidson, Professor of HPB Surgery, Royal Free and UCL, London

Professor Davidson contributed a "Viewpoint" article on CC surgery to AMMF a little while ago. To see this, go to:

<http://www.ammf.org.uk/article-3-surgery-for-cholangiocarcinoma>



Dr Shahid Khan

From Dr Shahid Khan

AMMF is the UK's, if not Europe's, only dedicated cholangiocarcinoma charity. They have done a huge amount to promote awareness regarding cholangiocarcinoma and to support patients with this cancer as well as clinicians and researchers fighting it. Their support has been invaluable to our own research programme regarding trying to find early biomarkers of cancer.

Cholangiocarcinoma remains a relatively "orphan" cancer in terms of research and awareness, despite being the second commonest primary liver cancer in the world and is responsible for over 1500 deaths each year in the UK alone. Ongoing efforts are needed to continue raising awareness about cholangiocarcinoma and to find better and earlier diagnostic markers, as well as more effective therapies. I fully support AMMF in their important work.

*Shahid A Khan, Clinical Senior Lecturer & Consultant Physician,
Department of Hepatology & Gastroenterology, Imperial College London*

Dr Khan has previously written on CC for AMMF, see:

<http://www.ammf.org.uk/article-1-overviewdr-s-a-khan/>



Mr Hassan Malik

From Mr Hassan Malik

Cholangiocarcinoma is a rare form of liver cancer that is increasing in incidence. The only option for potential long term cure is specialist liver surgery which is offered in a small number of hospitals throughout the UK. I fully support the excellent work that AMMF are undertaking in raising awareness of this disease amongst both patients and doctors in order to ensure that all patients are seen as a matter of urgency by specialist liver surgeons and oncologists.

Although surgical removal of the tumour is the only option for cure, only a small proportion of patients are deemed operable. The mainstay of non-operative treatments for this disease involve relief of jaundice; chemotherapy and Selective Internal Radiation Therapy (SIRT) has recently been approved by NICE for use in this disease.

In order to reach our ultimate goal of curing this disease, basic science research and clinical trials are crucial. In the UK we have a strong tradition of clinical research. Doctors, scientists and patients working together should enable us all to make advances in treating this rare yet serious condition. AMMF supports, and will continue to support, this admirable work.

***Hassan Z Malik**, Consultant Hepatobiliary Surgeon & Clinical Lead,
University Hospital Aintree NHS Trust, Liverpool*

To read more about the work of Mr Malik and the team at Aintree, go to:
<http://www.ammf.org.uk/2013/07/02/discovering-the-aintree-attitude/>



*Dr Salvatore Papa
and his team*

From Dr Salvatore Papa

Cholangiocarcinoma may be considered a rare tumour, however it is the second most common primary hepatic tumour and its incidence is increasing. Besides this, cholangiocarcinoma is considered a 'silent killer', as it is difficult to control and hard to detect in its early stages.

With the support of AMMF we are working on understanding the molecular basis of cholangiocarcinoma in the hope that, when we have more understanding, novel candidate targets may become attractive for drug research.

***Salvatore Papa**, Head of Cell Signalling and Cancer Group,
The Foundation for Liver Research, Institute of Hepatology London*

For more information on Dr Papa and the research work AMMF is supporting, go to:
<http://www.ammf.org.uk/2013/05/17/grant-for-icc-research/>



*Professor
John Primrose*

From Professor John Primrose

Cholangiocarcinoma is one of the most difficult cancers to treat. Surgery is technically very difficult and demanding for patient and the surgical team. But progress is being made. Centralisation of surgery allows more patients to benefit from high levels of surgical expertise, and I am pleased to support AMMF in their work towards ensuring operable CC patients get to these specialist surgical centres.

Studies have demonstrated benefit from chemotherapy and several more chemotherapy trials are now being funded. The first major study on chemotherapy in addition to surgery is almost complete and this study, CRUK's BILCAP – which AMMF has helped to fund with several grants – also collects cancer tissues and is enabling groundbreaking laboratory research. New studies are in the planning phase and will maintain the UK's position at the forefront of research in the treatment of this disease.

***John N Primrose**, President Association of Surgeons Great Britain & Ireland,
Director Hampshire & Isle of Wight CLRN,
Professor of Surgery, University Surgery, Southampton*

For more information on AMMF's involvement with the BILCAP trial, see:
<http://www.ammf.org.uk/grants-for-research>



*Professor
Daniel Palmer*

From Professor Daniel Palmer

The specialist cholangiocarcinoma team in Liverpool is committed to improving outcomes for patients with cholangiocarcinoma.

Since surgery currently offers the only hope of cure, with the support of AMMF, we are embarking on a clinical trial of the role of treating patients with 'borderline' resectable tumours with a course of chemotherapy prior to their operation to investigate whether this can increase the number of patients able to undergo successful surgery.

***Daniel Palmer**, Professor of Molecular and Clinical Cancer Medicine,
Institute of Translational Medicine, University of Liverpool*

To read more about the Liverpool team, go to:
<http://www.ammf.org.uk/2013/07/02/discovering-the-aintree-attitude/>



AMMF and the Imperial Cholangiocarcinoma Research Team – l to r: AMMF Trustee Harry Corrigan, Professor Simon Taylor-Robinson, Dr Verena Horneffer van der Sluis, Dr Shahid Khan, AMMF's Helen Morement, Dr Chris Wadsworth, Dr Abigail Zabron, Dr Simon Ralphs, Dr Nimzing Ladep.

From Dr Christopher Wadsworth

AMMF is unique in the UK in its specific focus on cholangiocarcinoma, an uncommon but devastating disease.

AMMF's funding of CC research, and support of patients with CC and their families, is invaluable.

Christopher Wadsworth, Consultant Gastroenterologist and HPB Physician, Hammersmith Hospital, Imperial College Healthcare NHS Trust, Honorary Clinical Research Fellow, Imperial College London

Now a Consultant Gastroenterologist and HPB physician, for several years Dr Wadsworth has been involved in researching a “multimodality” approach to improving diagnosis, working in three specific areas: Genetics, Proteins and Imaging. To read more about this, follow the link:

<http://www.ammf.org.uk/2013/04/13/imperial-college-cc-research-update>



Dr Hayley Whitaker

From Dr Hayley Whitaker

It's a huge privilege for us to work on cholangiocarcinoma and raise awareness of its existence and the need for more research within the scientific community. It's very motivating for us to know that any progress we make towards earlier detection and treatment could have a huge impact the lives of patients.

With AMMF's support, we are currently working on a new biomarker that can detect cholangiocarcinoma but doesn't give a positive result when there is just inflammation or normal tissue. We are currently looking at the function of this protein marker in cells to see if it could be developed further into a treatment for cholangiocarcinoma

Hayley C Whitaker, Cambridge Research Institute, CB2 0RE

AMMF has been pleased to support Dr Whitaker's BI-010 work. To read more about this, go to: <http://www.ammf.org.uk/grants-for-research>



*Dr John
Bridgewater*

From Dr John Bridgewater

The AMMF is the primary user group for cholangiocarcinoma and gall bladder cancer in the UK and fulfils a central role in supporting patients and families through illness.

Through the AMMF, patients and carers are finding a voice and an identity to help themselves and others. A key role is its advisory role in the national and international research programme in which the UK has led the world. The AMMF support for research activities and, in turn, the ability to inform and advise users is an increasingly important part of overall research activity, working to improve the outcome for all patients.

***John Bridgewater**, Senior Lecturer and Consultant in Medical Oncology (specialising in HPB malignancy), UCL Cancer Institute, London*

Follow the link to hear Dr Bridgewater talk about cholangiocarcinoma and the gemcitabine/cisplatin study: <http://www.ammf.org.uk/cholangiocarcinoma/treatment-options-2/chemotherapy>



*Professor Simon
Taylor-Robinson*

From Professor Simon Taylor-Robinson

The AMMF has been critical in raising public awareness of this terrible condition. All too often, patients and their families are left with too little information on treatment options – and clinicians themselves are often unsure, as the condition is rare and dedicated expertise is thin on the ground in many areas of the country.

The AMMF has been a really important portal for information for patients and for their relatives and on the other hand, has promoted research into cholangiocarcinoma with dedicated research grants to teams of scientists who are working on the cause of the problem – and potential cures. AMMF has also encouraged treatment guidelines to promote a treatment gold standard nationally and internationally.

In future, AMMF will be working with parallel organisations in Thailand, an area of the world where cholangiocarcinoma is commonest. It is hoped that this international collaboration will lead to scientific, treatment and patient care breakthroughs.

***Simon D Taylor-Robinson**, Professor of Translational Medicine, Clinical Consul of the Faculty of Medicine, Department of Medicine, Imperial College London*

To read more about AMMF's Thai connection, go to:
<http://www.ammf.org.uk/2013/06/18/towards-a-thai-connection>



AMMF is the UK's only cholangiocarcinoma charity, and is dedicated to raising awareness, supporting research and providing information on this disease.



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