



AMMF

THE CHOLANGIOCARCINOMA CHARITY

Facebook Guest Posts  
from February 2013  
Cholangiocarcinoma Awareness Month

[www.ammf.org.uk](http://www.ammf.org.uk)

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## CC DAY 1 – GUEST POST *from Tom Morement*

It's the first day of February and the beginning of CC Awareness Month, so I'm starting the month off with a quote from Franklin D Roosevelt:

*"To reach a port, we must sail – sail, not tie at anchor – sail, not drift"*

This is true with most goals in life, because if we want to achieve something we must set our sights and actively sail towards that end goal, without getting tied down or ending up adrift.

AMMF has a goal, a goal to reach as many people as possible and make them aware of the devastating disease that is cholangiocarcinoma, as well as funding research into early diagnosis and possible treatments.

This is a long trip and like most ships we need a crew, a crew to help us keep afloat, a crew to help us stay on course and a crew to help us save lives, and by taking part in this Awareness Month you are forming part of that crew.

So "welcome aboard" and I look forward to reading all your posts in the month ahead!

**Tom Morement**

*AMMF Trustee (... and AMMF's trusty gopher!)*



*Photo shows Tom with the Olympic torch last summer.*

## CC DAY 2 – GUEST POST *from Malcolm Robinson*

“Do you want to run Grandad?” three year old Joseph enquires as we set off for a walk in the shadow of Ilkley Moor. Just for one second my mind wanders to a cup of coffee and the morning newspaper... Do I really mean, “No. I fancy a quiet hour with my feet up.” ?

My mind also returns to six months before Joe arrived into the world and a nervous doctor had to make possibly her first announcement to a patient in my position – “It’s cancer ... in the bile duct.”

My Google search pulls up the Wikipedia page and I begin reading the first part of the sentence until I get to – “Cholangiocarcinoma is considered to be an incurable and rapidly lethal malignancy ....”. Quite literally – a death sentence. So I won’t be around to hold my grandson’s hand.

I don’t read any more words although for me, hidden in rest of that sentence, is my reason why the answer to my grandson is, “Of course! I want to run and jump and laugh and skip and trip and head straight for the nearest muddy puddle ....”

The second section of the sentence reads ....”unless both the primary tumour and any metastases can be fully resected”. Further down the Google search page is a link to AMMF. At last a positive place to be. A place where questions are being asked.

The faces and stories that combine to make this unique, remarkable and much needed organisation are many and varied. So many of those whose stories we will read about during Cholangiocarcinoma Awareness Month and are brought together by AMMF were not able to benefit from the second part of that Wikipedia sentence as I was.



Grandfathers or grandmothers wanting more time to run or maybe just to sit and watch. Those without a life partner each and every day or without a sister or brother, mother or father but, always and especially, those young children without a parent – heartbreaking.

“Want to run Grandad?”

“You bet I do, Joe ... for as long and as far and as fast as I can ... and until AMMF finds some answers to a much different question.”

*Photo: Malcolm and Joseph  
“Want to run, Grandad?”*

## CC DAY 3 – GUEST POST *from Sharon Solomon*

Wow, it's that time of the year again, Cholangiocarcinoma Awareness Month! And guess what I am still here, still going, not so strong, but here no matter what!

I would like to thank Helen and AMMF for once again giving us the opportunity to share our stories with everyone.

I was first diagnosed with CC in March 2011, what a shock to all of us! I had the right side of my liver removed in April 2011 and after recovering from that and starting the BILCAP Trial, I had constant tests to check on the CC. In November 2011 they found that it had metastasized to the Left Lung, in March 2012 they found another tumour on the Lymph Gland in my neck. They then decided to try Chemotherapy to see if it would help.

In May 2012 I started my Chemo which consisted of Gemcitabine and Cisplatin on a weekly basis for 3 months then fortnightly for another 2 months. It was the most awful experience I have ever had, I thought I was dying, I have never felt so sick in all my life. If it was not for all the love and support from my hubby Ronnie and our children I don't think I would have made it through it!

In November 2012 I was told that the tumours were not growing anymore but they would have to operate to remove them. On the 17th January 2013 I finally had a Neck Dissection to remove the tumour on the Lymph Gland. I am now slowly but surely recovering from this operation and waiting for a date to remove the tumours on the lung. Had my stitches removed on the 29th January and guess what, the tumour on the Lymph Gland was not Cancer, but a form of TB, they have sent the sample for restraining and will hopefully confirm which form of TB very soon. Of all the things to happen how on earth could I get Cancer and TB at the same time? Makes you think doesn't it?

CC is one of the most debilitating diseases I know of, there are days when I can barely get out of bed, and days when I feel ok. But with a lot of faith, love and support from everyone, I know I can get through this. I am a survivor and determined to get through it. In the past year I have been lucky enough to have seen my beautiful granddaughter Lexie have her 1st birthday and she continues to be my inspiration in life, one of my many reasons to keep fighting the fight!

I would like to thank my amazingly wonderful husband Ronnie and all our children Angelique, Steven, Monique and Chris, Mercia and Marcelle, for all their love and support and help with everything. Also my amazing mom and dad, my wonderful Auntie Olwen, my cousin Maryann and all my family and friends for all their support too!! My friend Anthea for being my shoulder to cry on even though it has been a tough year for her too as she has just lost her mom to cancer.

Thank you once again Helen for being there constantly for each and every one of us! I continue to pray for everyone that is suffering from this terrible disease.

With love to you all

Sharon xxxxxx



**"You raise me up"**  
Celtic Woman, live  
at Slane Castle



## CC DAY 4 – GUEST POST *from Nancy UR*

*In Loving Memory of my son, John-Patrick Ur, who lost his battle at age 31.*

There is really nothing good to say about cholangiocarcinoma. It turns your world upside down.

When my son was initially diagnosed, I couldn't breathe. It was like being stuck in a nightmare from which you could not wake. The doctor visits, ERCP surgeries, chemotherapy treatments, chemo-embolizations, emergency room visits and hospitalizations seemed never-ending. John wanted to try everything ... not just for himself, but for the others who would be diagnosed after him. He valiantly participated in clinical trials, which oftentimes sapped his strength and made him feel pretty darn lousy – but he chose to fight.

After his death, I thought my life would never go on. But I did make one promise to myself. And that was that John's life would make an impact on lives in the future. With that in mind, I asked everyone I knew (and some I didn't) to celebrate John's life every year on his birthday. So, on St. Patrick's Day, I remind people to do something wonderful for someone else, in the form of volunteering or donating or just by being kind to someone else. This is my way of keeping John's spirit alive. He was a very giving young man, and I hope to honor him by continuing this tradition for as long as possible.

Through the Cholangiocarcinoma Foundation and AMMF, I have "met" some very good friends – people who are or have gone through the same thing as me. I am lucky enough to be traveling from the United States to London this upcoming summer and will meet, in person, a few of these wonderful folks. These foundations helped me keep my sanity during this difficult trial in my life, and I am not sure I could have managed without that support.

I very often will tell people that losing my son was like losing a leg ... I miss it terribly but have learned to walk again, with crutches and a limp, but I AM WALKING!!!



*Photo: John on a visit to Florida.*

## CC DAY 5 – GUEST POST *from Sarah Eden* (Marketing & PR for AMMF)

Over the past year I have worked with Helen and AMMF to further awareness of the awful disease cholangiocarcinoma.

I still find it so shocking to think that only 5% of those diagnosed with CC are likely to survive beyond a year.

I have spoken to some truly amazing and lovely people in the last 12 months, including Malcolm Robinson, Helen Tanner, Marcella Smith and David Armstrong who have all given up much of their time to participate in press and radio interviews.

Helen is such an inspiration. She is dedicated to AMMF, which is such an incredible support to those diagnosed with CC. She works incredibly hard supporting the medical profession in its search to improve knowledge about why CC arises, its diagnosis and treatment. Real progress is being made.

Thank you Helen



*Photo: AMMF's Sarah Eden.*

**Helen's comment:** Since Sarah has been involved with AMMF, from a standing start and knowing nothing about CC, she has taken our work to heart and has become a true campaigner for the cause. Her determination and good contacts have been instrumental in achieving more quality media coverage than ever before, at both local and national level. For myself, I am humbled by her comments ...

## CC DAY 6 – GUEST POST *from Helen Morement*

I've spent quite a while thinking about my post today, Alan's birthday, and most of the time my mind has been circling round one subject –

It's an odd thing, isn't it, Love – you never know when it's going to come or when it's going to leave ... and sometimes you don't value it as much as you should ...

Back in the late sixties life was fun, and we all had the feeling there was a long, exciting, unknown future stretching out ahead of us. So, when my friend and I set off for a week's carefree holiday that long-ago summer, what happened was the last thing on my mind.

With one glance, I was bowled over by that ready, open smile and those gorgeous clear green eyes – I had met Alan, and life would never be the same again. Fortunately for me, the feeling was entirely mutual – something I have never quite got over – and by the end of the holiday, we were both convinced we had found the love of our lives. (What my parents had to say re holiday romances, I'm sure you can guess ...).

We married five years later – I think by then we had begun to prove we would stay the course – and eventually our son Tom arrived, which made our little family feel complete.

The years passed – and then out of a clear blue sky the most unwelcome visitor ever appeared, and decided he just wasn't going to leave. Cholangiocarcinoma.

He'd probably been lurking around for a while, but chose to make an appearance at totally the most unexpected moment. A lovely relaxed Sunday lunch with friends at the end of November 1997 – chatting about our Christmas plans and our skiing trip at New Year, and looking forward to Tom coming home from school for the Christmas holidays – that was the last 'normal' day we would ever know.

If we had ever been asked how we would cope faced with what we were told two weeks after that November day, I'm sure we would both have been unable to answer. How do you cope when your life and your future is about to be snatched away from you by some unknown stranger you are totally powerless over – by a disease the medical world had no answers for?

Back to where I came in – if anything positive came from this situation it was that knowing time is limited has an incredible focusing action on the brain. It gave us the time to talk and to realise, through all the madness and mayhem a disease like CC brings to your life, the wonderful gift we had been granted in our lives was the one thing this disease could not damage or ever take away, and that was – love.

In the last birthday card Alan gave me were the words, "Isn't it wonderful we were both in the same place at the same time, and we found each other." And today, on Alan's birthday, despite everything, my answer is still, "Yes, it is."

For you, on your birthday Alan, it has to be Leonard Cohen – and this time, with the addition of the utterly sublime Webb Sisters. xxx



**"If it be your will"**  
Leonard Cohen with  
the Webb Sisters



## CC DAY 7 – GUEST POST *from Matt Jackson*

Chris Jackson was an amazing friend, father, and husband. I could use an endless list of celebratory nouns such as 'loving', 'supportive', 'funny' and 'forgiving' to describe him, but these words took on a whole new and unique meaning when you actually knew him. This was the true wonder of Chris; a man who could transform a rainy Sunday afternoon into a memorable and heart-warming social gathering; a man who made life more enjoyable for everyone he knew just with his presence.

This is why it is so saddening, and hard to accept at times, that his life was snatched away by a rare cholangiocarcinoma cancer at such an early age. Particularly, when decades of research devoted to more common forms of cancer are edging us ever closer to not only palliative, but curative cancer treatment.

Please help in anyway you can either through fund raising or spreading awareness of AMMF, the only UK cholangiocarcinoma charity, so that we can keep more people like Chris in the world a little longer.

Thank you, Matt Jackson



*Photo: Chris Jackson.*

**JustGiving™**

## CC DAY 8 – GUEST POST *from Liz Heywood*

A tribute to my wonderful Dad, John Smith, who passed away from CC a mere seven weeks after diagnosis...

Until that fateful day in May 2009 none of my family had ever heard of cholangiocarcinoma. My Dad didn't display any of the classic symptoms that go with CC, just blood results that were unusual. There began the rollercoaster ...

Sadly, my family and I didn't discover the wonderful Helen Morement and AMMF until after my Dad's death. What a wonderful support Helen has been. Through AMMF I have 'met' some wonderful people and made friendships through the common bond of CC.

I have a Justgiving page in memory of Dad and in 2013 will 'walk' the race for life again for AMMF!!!



*Photo: John Smith.*

**JustGiving™**

## CC DAY 9 – GUEST POST *from Marcella Smith*

I am sure that many of you will be able to relate to at least one or more of these words, all of which are full of pessimism and despair. My hope is that in the future we can change the words to more positive ones borne out of research that will enable early diagnosis and mean a high percentage of curative treatment for CC patients.

It is always uplifting to hear success stories, but there are far too few. By raising awareness, funding and research I hope that the treatment for CC improves so that CC is not a word of fear and dread.

I support AMMF in memory of my much loved husband, Stewart – 14.5.1956 – 05.09.2011.



**"You're Missing"**  
Bruce Springsteen,  
live in Barcelona 2003

### CANCER

Hideous

Outraged

Lonely

Anxious

Nightmare

Grief

Infection

Outpatient

Cry

Anger

Resection

Chemotherapy

Impossible

Nervous

Outlook

Mestastasis

Afraid

## CC DAY 10 – GUEST POST *from David Tutssel*

My darling wife, Mary, lost her battle with this horrible disease on 28th June 2011. It all seems like a lifetime ago now, but that day will be one I can never ever forget.

She was a beautiful, kind and loving person who always wanted to see the best in people and not the worst. It took the doctors quite a long time to work out what was wrong, and clearly by then it was too late. They operated to remove a large part of her liver in a long and complicated operation that also necessitated removing and replacing part of her diaphragm.

Mary was put forward to participate in the BILCAP trial, but blood tests and then further scans showed the cancer had already spread. Chemotherapy followed, and then after the cancer spread to her brain so did Radiotherapy. Throughout all this Mary took everything that came her way with a smile on her face surrounded by her loving family. “I’m fine” she’d always reply when we asked how she was. And she was. She really was, despite everything, happy and full of so much joy. I don’t how she did it, but it encapsulated everything about her.



Only once, on the day she found out she wasn’t going to get better, did she tell me she was scared, as she wept in my arms and asked not to let go of her hand through what she had to face. I was still holding it when she died.

Please support AMMF as they look for a cure, and to help people get diagnosed more quickly, so that one day nobody will have to suffer in this way.

Dave Tutssel

*Photo: Mary & David.*

## CC DAY 11 – GUEST POST *from Julian Hundy*

*In loving memory of my lovely Mum, Anna Philpott.*

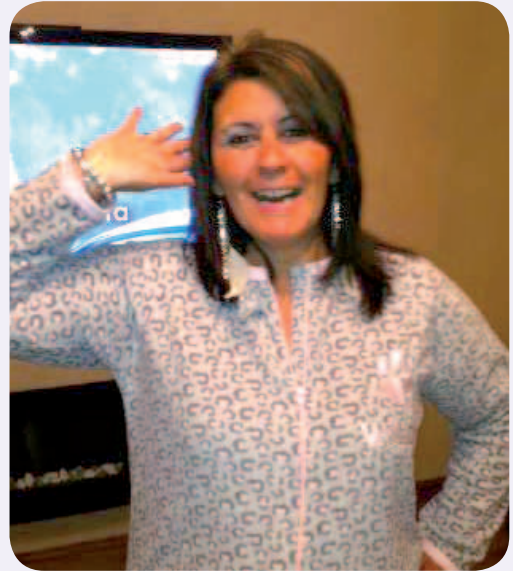
Mum was diagnosed with cholangiocarcinoma in January 2012. Like many people diagnosed, the disease was found too late.

The strength she showed through her treatment, hospital admissions and chemo was absolutely amazing. Mum protected us all and I think she knew more than us that the inevitable was going to happen. She sadly passed away at home on the 5th August at the age of 49.

It's hard to know what to say or do when you lose the heart of the family.

Next week I'm running the Brighton Half Marathon to raise money for AMMF and to echo something Helen Morement said; 'It's too late to save the special people that have gone from our lives far too soon, but if we can work towards a future where other people and their families don't have to go through this, then that will be the best tribute we can give our loved ones.'

'Live life to the full' ... and Mum, that's what I'm gonna do. Love you and miss you so much. xxx



*Photo: Always the life and soul, even in a onesie ...*

**JustGiving™**



## CC DAY 12 – GUEST POST *from Rebecca West*

This is dedicated to my beautiful best friend Helen Smith who died of cholangiocarcinoma in October 2010, just 35 years old. She is loved and missed by so many every single day.

### *Helen*

When loss leaves a space only your face can fill,  
I still find my heart thaws thinking of a time before ...

My dear friend we were so young  
and Saturday night meant dancing at 'The Venue'.  
Your laughter, your curls bouncing and all of us prancing  
and knowing all the words of all the songs  
and Monday still far enough away to cast no shadow.  
It seemed so simple, so right,  
Distilled to bring us pure delight.

I am held in your smile  
and for a while I rest in the memory.  
This place is the past we shared,  
It is lit by laughter and innocence.

We are life-lost best friends,  
we are girls together,  
Then brides and wives and mothers.  
Then there is this space left by loss.

A place only your face can fill,  
And today's forecast is the threat of ice.



*Photo: Rebecca (l) & Helen.*

## CC DAY 13 – GUEST POST *from Gavin Strachan*

*In memory of my Dad – Ronald John Strachan 12/7/1944 – 10/12/2009.*

The summer of 2008 is one that I will never forget, cholangiowhat? What the hell is that? I guess that all of us here would have thought that after hearing the word Cholangiocarcinoma for the first time. Awful word, awful disease and why does it seem to affect the nicest people out there?

It is coming up for 5 years now since I first heard that word and cholangiocarcinoma first entered our lives. My dad was diagnosed back in late summer 08 with inoperable CC. He was looking forward to retirement and all that that would bring, then this monster first showed its ugly face. Usual symptoms, jaundice, itching, yellowing eyes and skin, then off to hospital for tests. Three weeks or so later everything changed and we got the confirmation that it was CC.

Treatment wise, surgery ruled out due to location of the tumour, too close to the portal artery. Chemo or PDT offered as treatment, dad chose the PDT with a metal stent inserted to relieve the jaundice. He chose PDT over chemo due to the lesser side effects of PDT. His choice and I supported him to the max.

Once the effects of the PDT wore off all was going well for a while bar the tiredness. Dad was able to get on with life, albeit it at a lesser speed, much lesser on some days but hey, we'll take that. Better than what things could have been. Then by mid 2009 the tiredness got worse, the nausea started then got worse and the tumour was growing again. Chemo now ruled out at this point as the duct was blocked and couldn't be cleared so the chemo drugs would not be able to exit the body. By end of November 09 dad was in the hospice and passed away on the 10th December 2009.



*Photo: Dad "behaving" himself at the day care centre's Halloween party!*

Not a day goes by that I don't miss my dad. Things get easier with time, but I still miss him loads. I miss his stupid jokes, even though most of the time they were not funny!

I miss his shouting at the screen when watching the football or the rugby, and I miss his moaning when I made him his favourite tea of steak, chips and fried onions ... apparently there were never enough onions for him and they always needed "crisping up more!"

I used to use 2 whole onions when making that for us and his response when I told him that ...., "Hmmm....." Ha!

My thanks to Helen and AMMF for the outstanding work that they do and also to the Cholangiocarcinoma Foundation as well. Two organisations and groups of special people that are very close to my heart. We will get there.

## CC DAY 14 – GUEST POST *from Debra Lance*

*Remembering Terry Kimber who died from CC on 17th September 2010, aged 49.*

As February is CC Awareness month it is fitting that Terry's tribute should be today – Valentine's Day – a special day for both of us.

Until Terry was diagnosed with CC neither of us had heard of it, likewise all our friends and family. In October 2009 Terry underwent a liver resection. Initially he seemed to be recovering well until just before Christmas. More scans etc followed and in January 2010 we were told that the cancer had spread to his lungs and that he could expect 18 months. Hearing those words was indescribable.



*Photo: Terry Kimber.*

Terry decided very bravely that he wasn't going to sit around and wait for the inevitable and made a list of things he wanted to do while he was able. Despite times of feeling very ill Terry was able to enjoy some fun experiences including his lifetime dream of driving an Aston Martin! We went on a Mediterranean Cruise and Terry was able to relax on board and was able to visit among other places Rome and Florence, two of the places he had always wanted to see. Terry loved visiting the castles and beaches in Northumberland and it was there that we had our last holiday.

In September 2010, Terry was admitted to hospital for tests but sadly his health deteriorated and he was transferred to the local hospice where he died peacefully.



**"Chasing Cars"**  
Snow Patrol's "Chasing Cars"  
was played at Terry's funeral

Terry was a kind, caring man, with a zest for life, a twinkle in his eye and a smile that could light up a room. A sociable man he had many very good friends who were always there for him and he has left a big void in many lives. As for me I'm gradually putting my life back together again, but it will never be the quite the same as it was before.

It was a privilege to have known Terry, to love him and to be loved by him.

## CC DAY 15 – GUEST POST *from Julia Wise*

### *Susan Wise – A Tribute*

Susan was my big sister. She was always there. She was brave, feisty, courageous, fiercely protective and she drove me nuts. We drove each other nuts, actually. She refused to admit she was ill (unless it suited her) or that she needed help (ditto). She was amazing, wonderful, infuriating and I miss her like mad.

She hated being in a supporting rôle, but she was so often a catalyst for others. It annoyed the hell out of her, but made her very proud, too. If I wanted to do something, but was too scared, she'd nag me until I did it; if she thought I ought to want to do something, but I didn't, she'd push, push, push me until I gave in (or told her to drop it – and then she'd feel hurt). Her reason for "knowing better" than me was always the same: "because I'm your big sister; I'm older than you". Well, she won't always be older than me – I catch her up next year – but she'll always be my big sister. I love her – always have, always will.

I achieved so much because of her encouragement and support; I went to Russia (a long-held ambition of mine), gave up my job and went diving on Gozo for 3 months, became a PADI Assistant Instructor, got through break-ups and breakdowns, faced many fears and overcame some phobias.

I never thought I had it in me to be a Carer; never thought I would have to be. Sue taught me how to do that, too; to be there, to make difficult choices and impossible decisions.

I hate cancer passionately – and cholangiocarcinoma more than any other because of the way it gouged away at my sister and ultimately took her life – but, despite all that, I'm prepared to acknowledge that it brought good things as well as bad. Sue and I grew much closer and she told me her 3 years since diagnosis, whilst she lived with me, were some of the happiest of her life.

I set up a JustGiving Page for AMMF, so I could do whatever I could to raise awareness of CC and raise funds to help eradicate it. At first, Sue was reluctant to be identifiable, as she wanted to be "Susan", not "that woman with cancer", but she was amazed at the supportive tributes which started to flood in. Soon, she had relaxed enough not only to let me be more open about our identities but also to help me decide which photos to put up. Before long, she had become very supportive of my campaigning and very proud of our awareness-raising successes.

Susan died last May, just under 3 years from her diagnosis with inoperable extrahepatic metastatic cholangiocarcinoma. She, too, wanted to spread the word about CC and, together, we continue to do so.

Please help raise awareness; please share my link.

Thank you. Julia.



*Photo: Sisters, Julia (l) and Susan*

**JustGiving™**



## CC DAY 16 – GUEST POST *from Lesley Clark*

*Remembering Chris Clark, 1949 – 2012. So much missed and loved.*

16th February 2012 – in the early hours my beloved husband, Chris, finally gave up his fight with CC.

“You are all sad because Grandad has gone. I will bring him back then you will be happy again”, the words of our three year old granddaughter a few days later.

One year on his loss is just as painful and the hole in my life is just as huge. On that day our family lost a husband, father, grandfather, son, brother, uncle and friend – all because of a disease which showed little sign until it was too late.

Chris was only 62 when he died, but fortunately had been able to enjoy a few years retirement before he became ill. We had been looking forward to the time I could retire and all the things we could do together – walking the dogs, spending time with our granddaughter, no longer needing to watch the clock ... He was a home loving person, always ready with a smile and joke, and always there. To quote my daughter “he was a big hearted man taken too soon.”

Chris was diagnosed with cancer of the liver in December 2010 and a few weeks later discovered that it was cholangiocarcinoma – something we had never heard of until then. He been feeling unwell with an upset stomach in October 2010 and was finally encouraged to go to the doctor when this persisted for several weeks. We were not unduly worried as Chris had a “sensitive tummy” and was used to feeling unwell from time to time. He had also been diagnosed with type 2 diabetes several years earlier. Apart from that his only other symptom was feeling more tired than usual. Once he had the first ultrasound scan everything moved swiftly through CT scan to biopsy and six weeks later we knew the worst.



*Photo: Chris with granddaughter Lola.*

We were shocked to discover how short time was expected to be but we tried to make most of our last summer together, pottering in the garden, looking after our two lovely Labradors and enjoying barbecues and family parties.

Chris was the love of my life and the twenty years we had together could not have been happier. Life still seems quite unreal without him and very empty and I hope that this month will really help to raise awareness of this terrible cancer and that advances in research can give a chance of earlier detection and more effective treatment options. At least then our loved ones will not have gone in vain and their memories will be all the sweeter – and nothing can take the memories away.

“I love Grandad and I want him back now!” a comment from our granddaughter just a few days ago. To that I reply “Ditto”.



## CC DAY 17 – GUEST POST *from Karen Williams*

*In memory of an amazing lady, my cousin Carol Melvin who lost her battle with cholangiocarcinoma on 19th December 2010, aged 42.*

Carol wanted to use her own battle with CC to do all she could to raise awareness of this devastating disease and to support AMMF and, although very ill, this is what she did.

Carol was and still is a true inspiration. Her friends and family have carried on where she left off, and more has been done in her name and memory than she would have dreamed of ...

Carol would be so proud of each and every one of you who continue to increase the awareness of cholangiocarcinoma and to fundraise for AMMF.

Gone but never forgotten, always in our hearts ...

Love & miss you always, Carol xxx



*Photo: Carol on her wedding day in March 2010, looking so happy and beautiful, despite being in the last months of her illness ...*

## CC DAY 18 – GUEST POST *from Lee Philpott*

This post is dedicated to my beautiful wife, Anna Philpott, who died in August 2012 at just 49 years old, because of the dreadful unknown disease that is cholangiocarcinoma.

Looking back now, I am so glad that we lived our life together to the full, did the things that we wanted to do and went the places that we did instead of putting it off “til tomorrow”. As Anna always said “life’s too short, you don’t know what’s around the corner” and we most certainly didn’t.

We travelled the world together and I try to remember all the good times I had with such an amazing person rather than focus on the short time when things were at their very worst for us – I know that’s how Anna wants me to treasure the memories of the time we had together, but it’s not easy.

Anna refused to let her illness get her down and never once stopped being the life and soul of any social gathering, even when she knew her chances of beating cancer were becoming fewer and fewer. And she did know more than she ever told us about what was happening to her, but that was Anna – always the strong one who never wanted to be a burden to anyone at any time.

I will never ever forget the love and the all too short life that we shared and I miss her more and more every day that we are apart.



*Photo: Lee with Anna in Goa, 2011.*



**“I wanna dance with somebody”**  
Whitney Houston

On June 8th me and a team of 10 friends and family will be taking part in the NightRider cycling challenge, an overnight 62 mile journey on bikes around London, hoping to raise at least £2000 for AMMF in the hope that we can work towards a future where other people and their families don’t have to go through what we have.

The link to the left is to Anna’s favourite sing-a-long song.

**JustGiving™**

## CC DAY 19 – GUEST POST *from Andrea Fear*

*In loving memory of my precious Dad, John “Mac” Clark, who sadly passed away 2 years ago today.*

“If ever there is tomorrow when we’re not together... there is something you must always remember, you are braver than you believe, stronger than you seem, and smarter than you think. But the most important thing is, even if we’re apart... I’ll always be with you.” (A.A.Milne)

I was always a Daddy’s girl, and we shared that special bond that many dads and daughters share. My Dad was a true gentleman, kind, caring and brave. He was my hero, my best friend and someone I could always rely on.

Writing this post, I find it hard to believe it has been 2 years today since we said goodbye to Dad, some times it feels like forever, other times like it was only yesterday. Somehow as a family we have managed to get through it, hours have turned into days, days into weeks, weeks into months. Life has changed forever and getting used to the “new” normal has been and still is very hard.

I have found this year harder than last, perhaps because the reality Dad has gone forever has finally hit home. I miss our chats, and the sound of his voice, I miss his advice and the way that he would always be there to help out with anything and everything at the drop of a hat. I miss the way he seemed to go everywhere at a 100 miles per hour, many times I’d tell him off for opening the car door before I’d even stopped! and I miss seeing him sat in his chair, usually at the edge of the seat if he was watching the horseracing. I miss the smell of his aftershave, his hugs, his smile, his laugh and his unconditional love.

We all miss him, and it’s the little things that we took for granted that we miss the most.

CC is often advanced by the time of diagnosis and so surgery, currently the only potential cure, is not an option. Only 5% will survive one year from a diagnosis, sadly Dad wasn’t to be one of the 5%, he survived 10 months.

I look back at those 10 months and wonder how we managed to get through them. Whilst the CC was determined to take my Dad away, it couldn’t break the bond we shared, in fact it made it stronger. Not once did Dad complain, it was never “why me?”, instead “why not me?”. Despite everything he was going through he never failed to greet everyone with a smile. He fought this disease with great dignity and courage and a braveness beyond belief. I am proud to say I am his daughter.

*“To the world he was one, to us he was the world”*



*Photo: John “Mac” Clark.*

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## CC DAY 20 – GUEST POST *from Nicola Othmani*

From now on CC, and it's taken me over a year and a half to be able to look at the letters like this, you will now mean in my world 'Cheerful Charlie'. When I look at those two letters now I try to focus on sunny, happy memories of my lovely Dad, Charlie, instead of the intense feeling of fear, the unknown and, ultimately, the two letters that took my beautiful Dad out of my life forever at a time when I was so excited about sharing the next chapter of my life with him, one I had waited a decade for – becoming both a Mum and a wife, marrying my rock Fou, my soulmate, and having a little family of my own.

You always said it would happen, Dad, and then when it did you were not here any more to know that as always, you were right. I miss you watching the girls, Samiah and Caliana, grow – you were just so much fun, a quality that seems to be getting quite rare these days in life, just so so much fun. I adore my little family, Dad and I hope you are looking down each day and that I am doing you proud. You're probably having a little giggle saying, 'See Blondie, your old Dad was always right!'

Our girls are so smiley and cheerful by nature that I feel like you are in my life each and every day through them, Dad. I cherish time with my family and making memories that can't be taken away, As we know, time itself is something that can be cruelly ripped out of our lives in a heartbeat. I thank you from the bottom of my heart for giving me great family values and your love of getting the biggest smiles, the warmest feeling and such pleasure from the things that cost absolutely nothing at all.

I chose to write this today on Feb 20th, the day I return to work from my second (and last ever!) lot of maternity leave. My first maternity leave was so hard, watching my beautiful Samiah come into the big wide world and at the same time watching my strong Dad fight for his life. To then lose you a week before my wedding day was the saddest time of my entire life. But I drew on strength that you had shown me to continue to enjoy and live my life to the full, from getting married to the birth of our beautiful second baba, Caliana – born on your Mum's birthday.

I continue to miss you more as time goes by. Every little girl needs their Daddy and I was the biggest Daddy's girl going! I miss our chats, our hugs and the laughter. God Dad, we used to laugh til we could laugh no more and, like I have said a million times, I laughed the hardest when I laughed with you. No one can ever fill the hole that is left in my life and I know I have changed as a person. I don't think people realise how much they need their Dad until they are not with you any more. I face everything in life with a smile and as much positivity as I can, I learnt from the best. Whilst some things are incredibly tough without a Dad's advice or guidance, I am very lucky to have such an incredible support network and people that are always happy to help in a heartbeat.

As a family we are now looking forward to the birth of Chris' son in less than a week, your 6th grandchild. Family is so precious and I made up the following to reflect what it means to me ...

F - Forever  
A - Adore  
M - Mine  
I - I  
L - Love  
Y - You all

Know you are in our hearts, our thoughts and our minds every single day 'Cheerful Charlie'. Fou, me and the girls miss you so very much. All our love is winging its way up to you in heaven.

My family is thinking of everyone who has loved and lost, and those fighting this disease, every single day. We wish you strength and love. Helen for all you do, thank you is quite simply never enough. If there were more people in the world like you then this world would be a much better place.



*Photo: Charlie's granddaughters, Samiah and Caliana*



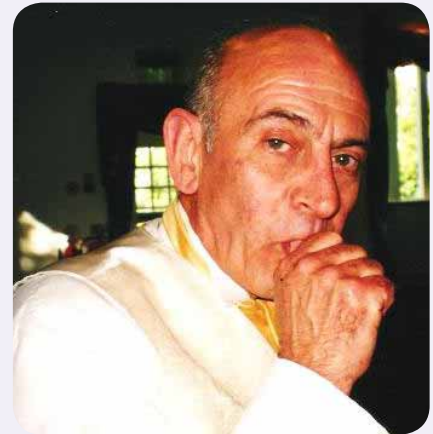
## CC DAY 21 – GUEST POST *from Derek Owen*

### *Happy times, in memory of our Dad, Arthur Owen...*

It was a Sunday afternoon and my father was at my sister's for Sunday lunch. Mum noticed Dad was quite yellow, from then on it was a roller coaster ride into the unknown. So a few days later Dad was admitted to his local General Hospital. I jump in the car and a while later, I'm at the hospital and I catch the sight of him sitting in his hospital bed.

Pause for a moment... last time I had seen my Dad was about 6 weeks before and he was normal Dad (well, he wasn't really normal, he was a mischievous character at heart, but he was his normal normal self).

So to go from that to seeing him in a hospital bed, and a look of worry on my sister's face (she's a nurse and knows the signs)... we were shuffled into a room and in response to my sister and I asking the question, "What is it and how long has he got", the reply was "ah.. yes.. well... maybe 12 weeks, but it could be longer or shorter, we just don't really know what it is yet, but he's now palliative care". Whatever that meant, at the time I was clueless. In sets the numbness... and a somewhat draining process.



*Photo: Arthur Owen.*

We've always been a close – geographically separated family, but still very close, so this was making everyone tense and angst at the same time. We were then informed it was a very rare cancer called cholangiocarcinoma – I had trouble saying it let alone spelling it! It's a rare bile duct cancer.

So we knew what it was, and after researching what could be done (there wasn't much about it at the time), we came across a therapy known as PDT (Photo Dynamic Therapy), and there were trials in Germany and the UK at that at time.

Long story short – we managed to get Dad referred to a lovely, caring and extremely knowledgeable doctor, Dr Colin Ainley at the Royal London Hospital. Dad was in and out of the hospital on many occasions. In the period of 5 months he had 4 metal stents, a night on A&E! and many trips to the Royal London late at night when we didn't know what else to do, thinking "This is it!".

Dad wasn't eligible for the PDT trials at first, but his consultant pushed hard internally, and we got a "yes". Everything was looking positive for about a month, and then Dad started to go downhill. He was taken back in to his local hospital to drain away a large amount of fluid. Then for one last time we took him back up to the Royal London to his consultant to check on his PDT results and stents.

It was at this point we were told the awful news that the cancer had spread to behind his liver – and it was the size of a cricket ball... Wow. Your heart sinks, and that instinct you have to forever survive and the driving need to keep your father alive... is taken away from you in that split second. Then the inevitability sets in.

I don't know to this day what we thought would happen, maybe there was a glimmer of hope – our Dad was special and therefore he would get through this, and we would prove that he was stronger and more resilient than we knew and we would have more time with him, why not – were only given around 4-12 weeks to start with – why can't he keep going another few years! But it was not meant to be.

We then had the horrible conversations with him about his last wishes – as well as some very very funny moments with him – such as one of his last meals – all he wanted was a small triangle of bread and a triangle of cheese on top – about the size of a 50 pence piece – to which he replied "oooh that was absolutely lovely"...

We'd said goodbye to him on the Monday when his breathing became much laboured and we didn't think he was going to make it through the night... only for him to wake up the next morning asking for poached eggs on toast, and to put the crime channel on the tv! However, this was just another false hope moment or Dad being just bloody minded and determined to fight on.

Thursday evening, 3rd December 2009, our Dad, granddad, and loving friend – quietly passed away, with his family around him.

The grieving has taken its toll on us all, and for the first time in a while whilst writing this little note, I'm crying thinking of our Dad and the time we had with him. I feel lucky in a way that we did have that time, but it's also mixed emotions – some we are still experiencing.

To our Dad, we love you and miss you and wish every day that you were with us to be the naughty, cheeky granddad, but you live on in your children and grandchildren and you will forever be loved. We are truly blessed, as at 72 Dad had a full and active life, and met his grandchildren, this is brought home to me more when I read the AMMF guest posts, where other families have lost their loved ones at a much much early age, some having lost their children through this awful cancer.

Dad's favourite word in times of trouble was "hope".

To have hope – and he always did.

Love you Dad x



## CC DAY 22 – GUEST POST *from Nikki Greenall*

*Helen Smith 23.5 1975 – 26.10.2010.*

It is very difficult to breathe life into a piece of writing on a sheet of blank paper to make the essence of someone come alive when you read about them. In order to try and explain what Helen was like the best thing to do would be to set fire to the piece of paper to see it spark into life, crackle and burn with a flame so bright it would hurt your eyes to look at it. Because that is what Helen was like – a bright, vivid, beautiful young woman who was full of energy and vitality. She was a warm, living, breathing human flame that people were drawn to.

Sometimes in life you are lucky enough to find a special friend. Someone who changes your life just by being part of it, someone who makes you laugh until you can't stop, someone who convinces you that there really is an unlocked door just waiting for you to open it. This is what Helen was to me. The amazing thing about Helen is that she was so many different things to so many people, and the bottom line is that everyone loved her.

Helen died 2 years 4 months ago after a 14 month journey with cholangiocarcinoma that tragically was only ever going to have one outcome. She faced the situation with determination and courage and it was just heartbreaking to watch the demise of someone who had so much to live for, not least her young daughter Ella. The word cruel does not even come close to describing what this ruthless disease does to people and their families. What strikes me as particularly unfair is that cholangiocarcinoma doesn't even begin on a level playing field – as in a lot of cases the disease has progressed too far to have curative treatment. It is also relentless – I think we were all shocked at the speed with which Helen was taken from us. Thanks must go to Helen Morement and the team at AMMF who are doing what they can to find ways of discovering early diagnosis and successful treatments that give people longer with their families.

Helen will always remain the age of 35 and so will always remain young and beautiful in my memories. She won't have to worry about hairy facial moles, moustaches, blue rinses, false teeth and ear trumpets – that pleasure will be ours in years to come! For those of us lucky enough to have had Helen in our lives, we share a common cause that is to fundraise for AMMF. If money that we raise goes towards helping just one person survive this awful disease then it will be worth every drop of sweat that has gone into achieving it.



*Helen and Ella.*

A group of Hel's friends – The Pink Panthers – have taken part in the last 3 consecutive 'Race for Life' events on Bournemouth sea front, but I think most of us (or am I just speaking for myself?!) feel that our running talents have been utilised enough! This year we are discussing doing a 26 mile walk starting from Stonehenge and there has even been a suggestion that a bike ride in Africa would be a good activity in future years.

Personally I think a sponsored sunbathe in the Bahamas would be a good idea ... who knows where our fundraising activities may take us in the years to come? One thing is for sure – we will continue to raise money for AMMF – and I know Hel will be cheering us on from her cloud in heaven every step of the way.

Nikki Greenall Xxx

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## CC DAY 23 – GUEST POST *from Jane Stout*

Our Mum, Judi Kidd, was an amazing woman and never happier than when surrounded by her family. And we are thankful that that was how she died in November last year. At home with her family holding her hands and talking to her. That's something that we can be thankful for but considering that Mum had been fit and well until July last year, it is quite a struggle to be thankful.

Like so many other people whose heart-breaking stories we have read this month, we too had never even heard of cholangiocarcinoma until her diagnosis on August 14th last year. That terrible statistic - only 5% will survive one year from a diagnosis of CC – doesn't lose its impact no matter how many times we read it. We are increasingly told that a cancer diagnosis is not a death sentence, it is the sad truth that with CC it so often is.

Our cousin Jonathan Kidd will be running the Manchester Marathon in April, and in September my husband Richard will be cycling from London to Paris and, with a group of friends, I will be tackling the 100km Thames Path Challenge.

We can't help Mum any more but the money being raised by so many people for AMMF to fund research into this ruthless disease will hopefully help others in the future.



*Photo: Judi with her family.*

## CC DAY 24 – GUEST POST *from Brenda Dimeck*

*In memory of Jane 16.1.60 – 7.1.11*

Cancer, that unwelcome ‘intruder’ wasn’t a stranger to us three sisters. Two of us were already survivors. Genetic counselling complete, the third underwent elective surgery. Regular screening was set in place for even the next generation affected by our inherited rogue gene. That’s why, 5 years since our ‘little’ sister’s first encounter with cancer, our confidence in the liver resection to restore her to good health was not misplaced. Jane had been resilient before.

Nobody even suspected anything untoward, when two months post op, she presented with worsening back aches and indigestion that no remedy prescribed by the GP would settle. Not until another two uncomfortable months passed and subsequent tests, did Jane learn her life would be cut so short and so soon.

Years ago, with our young families we’d had some ‘good’ walks: Ingleborough in Yorkshire, Craigendarroch Hill in The Highlands, and more recently, a rare one up Clachnaben, just us three ‘girls’ and a bevy of dogs to name a few. But it was a fair October afternoon two years past at Fairburn Ings that the three of us took our last. Already we both could see gaping evidence of our sister’s weight loss, and our hearts were heavy.

We had to talk, and Jane apologised oh so needlessly that such a special time, a beautiful walk in that bird sanctuary should be marred with these details. She spoke of a hospice she visited regularly now, a church and a vicar, who many years ago had counselled her through a crisis, and a favourite song to be heard by those who would gather at her funeral service. So surreal, and we three linked arms on that path and choked back tears and walked for a long time until Jane was ready to rest. We prayed and her only real concern was for her boys.

That night two of us had a task. We had a new word, which was turning our family’s battle with the ‘intruder’ into a losing one. We quickly learned to spell ‘cholangiocarcinoma’ and needed to be armed and prepared as much as we could with any information on how it would affect the remainder of our sister’s life, so desperate were we to find some thread of hope in all those words. In our searches we quickly came across AMMF and tried to take in facts. Later we would find out Jane had already been here seeking advice.

So those ten weeks, one by one became a history of palliative care, hospital wards, tests, surgery, A&E, jaundice, more surgery and the hospice. Less than 48 hours before she died, our sister gave us the most memorable, beautiful smile. News she had been waiting for about her unborn, first grandchild and the CT scan of a healthy baby girl brought real joy to us all.

And someone said how many people would gather to honour our sister’s life, but he was wrong and three, or four times more people came and filled the church. One of Jane’s boys remembered a hymn from our schooldays and we sang ‘All Things Bright and Beautiful’, and those of us who truly believe the words in that old song tried to do it justice, but throats choked with sorrow don’t sing with such strong voices. Because of our ‘little’ sister’s return to the faith and God of her younger years, ‘Amazing Grace’ was an apt hymn. We all know that story about Jesus going to look for one lost sheep. As all her certainties slipped away, and hope was fading fast, Jane heard His voice, and had come back into the sheepfold. On Calvary’s cross He’d paid with His life for His flock, that Great Shepherd, and she wanted some strong reassurance and promise of eternal life in Heaven. Great hope and sure certainty was hers, because the Bible is all about that, about reconciliation and mercy for those who trust.

So, when it was all over and people had gone, we brought her favourite sunflowers to put there in a place she had asked for.

Recently her ‘boys’, her friends, nephew, niece, my sister and I, we’ve been thinking how we remember Jane with her beautiful smile, which could make you feel right, cosy and easy in her company, that’s a given. Her son called her his ‘best friend’. The nephew and special, close friends say she was an awesome, loving, loyal and non judgmental soul mate. My sister recalls Jane’s tender concern and protective nature for us all. I think of how she’d say, “Hello!” and made it so full of genuine pleasure; made you feel right special and valued.



*Photo: 1993 Top of Ingleborough. Jane at far right.*



We remember her selflessness, and the times she ran for Race for Life and encouraged others to do the same. That she ‘infiltrated’ and was competitive in the male dominated world of Yorkshire pigeon fanciers says a lot. And... could she sing!

This is our story – We add it to the rest and know that some have very hopeful testimonies. For those we are as delighted as you are, and thank AMMF for the incredible work you do towards fund raising for much needed research and creating awareness of this cruel cancer.

Thank you for reading this.

*And the song Jane wanted us all to hear, when we gathered at the church in her memory, a song she would sing to us when she was just 5 years old – “What a Wonderful World”*

## CC DAY 25 – GUEST POST *from Alison Symms*

A bit of a tenuous link, but a link nonetheless.

25th February would have been my beautiful Mum's 62nd and a half birthday (told you – tenuous!). Our CC journey began in 2010 and like others the signs of something not being right had been there for a while. With Mum's get on with it attitude she had put symptoms down to a previously diagnosed hiatus hernia before having a diagnosis of gall stones early in 2010. In May 2010 after developing jaundice (assumed to be gall stones causing a blockage) she was admitted to hospital where a procedure to release the blockage was unsuccessful and two biopsies later...

At this time I was 6 months pregnant and I feel that I should have asked more questions of Mum, of the doctors and Macmillan nurses and of the cancer.

Mum wanted to protect both me and my sister but we knew our time with her would be short, but not how rapidly she would deteriorate. Mum said she wanted to achieve two things – her 60th birthday and the birth of her grandchild in August. Edward was born the day before her 60th birthday and Mum died 7 weeks later.

I am so proud of my Mum and am relieved that she is no longer in pain and have wonderful memories of her, but Edward will never experience her love or amazing hugs. I now understand that very special gift of being a Mum and understand the unconditional love that you have for your child and to protect them no matter what.

So thank you to AMMF for being there for me at a time when I was ready to ask to all those questions. In sharing our experiences I hope we can raise more awareness and have more answers to these less "glamorous" cancers.

Alison



*Photo: Edward and his Grandma.*



## CC DAY 26 – GUEST POST *from Sandie Gapper*

BECAUSE I CAN, I decided to go for a swim at a pool in France ... negotiated the French system of how one goes about it, bought my obligatory black cap, waddled through the hotel in my obligatory white spa dressing gown and eventually arrived at the pool. I walked down a ramp into a zone of madness!

It's an indoor salt water pool, big, with different water moving 'things' in different parts of the pool. I walk into a waterfall and slip into five feet of salt water head first, regain composure, scramble up another ramp and collapse into some sort of cross between a geyser and a jacuzzi with hiccups. My feet are wiped away from under me as I cling on to a bar for dear life ... the water suddenly changes direction and I find myself standing upright but at a 45 degree angle!!

Sod that. I make my way out and fall into the calm salty waters of the next section ... I bump into something metal. Dear God, what have the French installed .... under water bikes? "Ah", thinks me, "no need for the gym today", as I attempt to clamber on. My feet can't reach the pedals and my ass is floating to the surface, resembling two rats in a wet sack having a judo fight ...

I lose total control and go head first over the handle bars into the path of an unsuspecting Frenchman who was enjoying the hiccup experience, but now has to contend with a totally insane British woman who has wrapped her legs round his for fear of being dragged into the next mad zone. He gently attempts to put me on my feet, but I've got other ideas while doing a Beth Tweddle act on his parallel bars! He finally frees me and I offer my apologies as I climb out of two feet of water, red, bruised and determined not to swim there again.



*Sandie Gapper ... diagnosed with CC 15/11/2011.*

But why am I telling you this ... simple ... because I can. I am one of the lucky few who could have a resection and it was successful. I am one of the small percentage who beat this monster and, yes, I know the recurrence rate is high, but I feel I have won. Through raising awareness at GP level and discovering early detection markers ... others too can feel like me ... I want to hear more people say ... because I can.

Does your GP know about CC?

Next year, I am mountain gorilla trekking in Rwanda to raise money for AMMF ... this amazing charity dedicated to CC.

If you want to help me, please get in touch with either myself or Helen at AMMF.

**BECAUSE I CAN!**



## CC DAY 27 – GUEST POST *from Jessica McMullen*

*In Memory of Tina McMullen 27-02-60 to 02-07-2011.*

My Mum had the usual signs of jaundice and was diagnosed with CC in December 2011. She survived 7 months of illness, septicaemia, stents, scans, drains, blood transfusions, sickness, pain, hospital superbugs ... she took a sudden turn for the worse and I held on to my Dad as we watched her slip away without the chance to tell her properly how much we loved her.

I don't want this story to repeat itself again, it's time to stop the mistakes, the doubt and the suffering. It's time we got to share more joy, success and hope and all my thoughts are with the families and friends of AMMF and all the fantastic people already mentioned this month who had to leave us this way.

Happy Birthday, Mummy. This is for you:



**"Wonderful World"**  
James Morrison



*This is my Mum and Dad on their wedding day, 26th February, 1983 – Happy Pearl Wedding Anniversary, Mum.*

As many of you know it can be harder and harder to find opportunities to remember our loved ones properly, although we never stop thinking about them every day. Thank you to AMMF for another chance to remember my Mum.

My Mum wanted her experience to help others so thank you again AMMF for helping her to achieve this. Millions of pounds are donated every year to cancer research and you help direct just that little bit to CC and fantastic work has been done, including the new CC Guidelines. I think communication is key as the same mistakes are being made across the country due to lack of knowledge and experience.

Everyone with CC in their lives needs AMMF. I only wish we found it sooner, but it has given me some comfort in coping with the aftermath of CC, and again I thank you for that as well.

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## CC DAY 28 – GUEST POST *from Helen Tanner*

Today is exactly two years since I first returned to work following liver and bile duct resection for CC. Like most people these days, one of the first things I did when I was diagnosed was to look it up on the Internet. What you find in that first trawl of sites doesn't make great reading - essentially not much hope of anything good! You start with what you are familiar with and therefore Wikipedia has a lot to answer for, although no one can say it is factually incorrect of course.



*Photo shows Helen at one of her fundraising tea parties ...*

I was lucky enough to be diagnosed quickly, and at an early stage, and was offered surgery – the only chance of a cure. I lost myself to the demands of my treatment for some time, and didn't go near the Internet for a while. When I was finally starting to feel better physically, I turned to the Internet to try to help with what was going on in my head. That's when I found AMMF. Here was a resource that seemed to care about positive things as well as being clear with facts; and finally some information about the care of CC patients in the UK. Helen works so hard to raise the profile of CC, whilst directing funds to vital research that will hopefully improve diagnosis and treatment in the future.

To try to help others avoid some of the “internet trauma” that I had, I would like to see AMMF being offered as a resource by hospitals treating CC patients, perhaps through the specialist cancer nurses – it would be simple for the details to be included in leaflets such as the one I was given before my surgery. A little challenge for 2013 Helen?

Thank you Helen, and all our CC family, for helping me through the last two years. I love getting involved in my fundraising activities and have a few more things planned for this year. Watch out for the latest from my great team at Waterside Practice – we had a “Purple Day” on 26th Feb in aid of AMMF, so no doubt Helen will be after some photos....

## CC DAY 28+1 – GUEST POST *from Angela Wandrag*

### *Lina Shoobridge 1957 – 2010*

One phone call in March 2010 from my big sister Lina (living in Virginia USA) turned our world upside down. She was in hospital: jaundiced and itching. I'd seen her weight loss when I'd visited her 6 months earlier but had put it down to the trying times she was experiencing in her private life. Soon after we heard the word cholangiocarcinoma for the very first time and then that terrifying statistic of 5% survival after one year. She had a stent put in with chemotherapy to follow.

Now I felt a very long way from my beautiful big sister: Lina was the life and soul of every party, a loving member of our close-knit family, she lit up every room she entered. Rod Stewart's biggest fan and a lifelong Arsenal supporter – even when living in the US – Lina worked hard, played hard and she loved to spend time with her children and her friends.

Discovering AMMF in the UK and the Cholangiocarcinoma Foundation in the US was such a relief and so very helpful. We felt helpless in England so in May we raised awareness and funds with a 'Friends for Lina' coffee morning at which our friends were incredibly generous.

Lina was determined to get this cancer out of her body, she really was the eternal optimist. She tried all kinds of therapies and foul tasting potions. A friend drove her up to Boston to see a specialist but nothing came of it. Chemo didn't seem to help so she pinned her hopes on being included in a clinical trial in August, but it turned out not to be available to her. Seeing Lina fade before us brought the family closer together than ever. Our immediate family stayed with her all that summer and we shared wonderful times including her birthday party at the end of August which she thoroughly enjoyed, managing to stay up until midnight. She was such a fighter, a joker and so grateful to everyone around her.

It was hard to see her two teenage children trying to cope with this craziness; we kept them close and made sure they knew there was a loving family here for them and always would be. Lina's amazing circle of friends had been fundraising to help pay the bills and had done all the chores and cooking. For me, setting up a Facebook group was an easy way to keep everyone updated all the way through to the end. We coped in any way we could, knowing that we wouldn't have Lina for many more months.



*Photo of Lina (l) with her brother and sister, August 2010.*

That time was cut even shorter when Lina suffered a heart attack in September, just days before she was due to fly back to England then to her native Cyprus for a final visit. A short stay in a local hospice then back to her own home with all the family and her methadone pack in place. Amazing 24/7 carers helped prepare us for the inevitable while giving Lina the dignified care she needed. Lina slipped away 10 days later with prayers and hands held over her.

The celebration of her life was a fitting tribute to such a bright light. "All Things Bright and Beautiful" was her all time favourite and we did our best to sing our hearts out for her. Never forgotten, always remembered.

Many thanks AMMF for the huge amount you do to raise awareness and funds for this killer. Maybe one day there will be ways of catching it early.



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

Special thanks go to everyone who was brave enough during CC Awareness Month 2013 to take part in AMMF's Facebook Guest Post feature – tears have been shed over these incredible stories of love, courage and support from those currently undergoing treatment and those who have lost precious people to CC. But there's been rejoicing, too, reading the "survivors" stories – who could forget Malcolm's, "Do you want to run, Grandad?", Sandie's French swimming pool adventure, or Helen's tea parties!!

For everyone in our CC Family, AMMF will keep working until the answers are found.



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