

AMMF - The Cholangiocarcinoma Charity
Cholangiocarcinoma Awareness Month - February 2012

Guest Posts appearing daily on AMMF's Facebook page during February

CC Day 1 - Tom Morement

CC is a horrible illness, but from all things some good can be found, and because my father died from CC the charity AMMF was born.

Never did I think that my father's death would result in a charity being set up which aims to, eventually, help others not to have to face the loss our family did.

I was proud of my father, and I am proud of the charity founded in his name.

CC Day 2 - Malcolm Robinson

'It's cancer'... 'Ok let's get on with sorting it out then'... 'It's called what?... 'I'll just have a look at the Wikipedia page'... 'Untreatable?'... 'Survival rate what?'... '6 hour operation?'... '6 months of chemo that might or might not work'... 'Let's see what support there is out there?'... 'You've not heard of it but I can join in with a general support group'... 'Phew'

Without AMMF the journey of whatever length - mine has been two years - would be just unimaginable. Thank you to all supporters with input in any form from medics to marathoners. I made it up a 3000 ft peak in the Yorkshire Dales last year to raise funds and this year I am doing an 'along' not up - Walking the Yorkshire Wolds Way (help me out with a 'C' please!). We hope to be joined by friends and family on the seven day stroll. Inspired by the David Hockney coverage we are going to make AMMF one of the 'taller trees' in its unique field.

CC Day 3 - Nikki Greenall

In Loving Memory of Helen Smith 23.5.1975 - 26.10.2010

I wanted to pay my respects to my remarkable friend Helen Smith who fought a strong and dignified 14 month battle with CC. When Helen was diagnosed I had never heard of CC before. The work that AMMF is doing to bring CC to the consciousness of the public is vital, as it affects so many people both young like Helen, and older.

I don't like to say that Helen lost the battle with CC - more that she came to a decision to put it to one side in the naughty corner and refused to enter into discussions with it in true deputy headteacher style! She was loved by everyone

who knew her and her characteristic blonde curls and amazing smile live on in all of our hearts. I know that she will be immensely proud of her husband Nick and daughter Ella.

I would like to dedicate a song to her, it was released after she died but I suspect she would have really liked it - so this is for you Hel and to anyone reading this who knew Hel, smile and imagine her dancing to this.

The Wanted - Gold Forever. http://www.youtube.com/watch?v=Fu_J4QPr8To

I will watch you in every sunset, I will chat to you in my dreams and listen to your laughter as it catches the winter wind. Love always Nikki xxx

CC Day 4 - Jillian Maclean

In memory of wife, mum and granny, Doreen Gilmour who lost her battle with CC one year ago today. She is in our thoughts always but particularly today.

In appreciation of the fundraising done by family and friends.

In recognition of the amazing job done by AMMF in raising awareness of this cruel and devastating disease.

CC Day 5 - Karen Williams

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

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

Carol has done more than she could have dreamed of to raise awareness of CC and so much good has been done for AMMF in Carol's name and memory - she was and still is a true inspiration.

In appreciation of all the fundraising done by friends and family - Carol would be so proud of each and every one of you who continue to increase the awareness of cholangiocarcinoma and to raise funds for research.

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

Love & Miss You always Carol xx

CC Day 6 - Helen Morement

Remembering Alan Morement (06.02.48 - 21.12.2000)___

Today, 6th February, is Alan's birthday.

When I close my eyes, I see my lovely man with his clear green eyes, and his gorgeous, ready smile - strong, caring and loving. And my heart aches because yet again I can't wish him a happy birthday or plan a surprise for him. Why is this? Because CC came into our lives like a thief and took away our future ...

So, instead of celebrations, I will remember the good times and listen to some of Alan's favourite music - Leonard Cohen, of course - and especially, because it is just so true (you speak straight to the heart, Mr Cohen), "There ain't no cure for love." Alan, you are in my heart on your birthday today, and forever. xx

<http://www.youtube.com/watch?v=bsDTqHL6Iro>

CC Day 7 - Brenda Dimeck

Our sister Jane in a photo taken a long time before we became personally acquainted with cancer, genetic counselling, cholangiocarcinoma and the grief of losing a much loved sibling.

So today as any other day, each of us with our own precious memories picture her with that beaming and winning smile, and because of her are proud to link up with AMMF to raise awareness of the work they do to fund research into CC.

Jane Seekins 1960-2011 Beautiful Lady.

CC Day 8 - Fiona Richie (Scotland)

Thinking today of those who, like my Dad, Derick McRobert, have been diagnosed with CC during the last year. Dad first heard of AMMF in February 2011, via Tom Gilmour (a former school pal) after the sad death of his wife Doreen. Little then did Dad suspect that, within 4 months, he himself would be diagnosed with CC. Having had an excellent annual Well-Man check in April, bloods perfect, he was concerned to notice, in late May, that he had symptoms of CC, as outlined on AMMF's website. Further blood tests showed a massive liver enzyme spike since the April test, which led to investigations, surgery and the CC diagnosis in June and subsequent chemotherapy.

As a family, we would like to give an aCColade to AMMF for providing aCCcess to such aCCurate information on their website. After Dad's diagnosis, we were floundering around on the Internet for information - and there it was, so easily

aCCessible on the AMMF website, with so much valuable input from families, who had been in the same situation, as well as from medical specialists. Personal contact from Helen Morement and Tom Gilmour too was so appreciated.

This is a thank-you, too, to all those who, through fund-raising activities, ensure that the research into this terrible disease can continue. Finding a means of earlier diagnosis would seem to be a key feature-certainly in Dad's case outlined above, only 5 weeks elapsed between a good LFT result and one that suggested problems, by which time there was already lymph involvement, showing how quickly things can happen.

Finally, a diagnosis of CC is, as we have found, a family affair, affecting all the nearest and dearest of those suffering from the hideous illness. Thinking of all such families today and wishing them the strength and courage to cope, whatever their situation. To prevent other families going through similar heartache, it is vital we put the aCCent on awareness-raising and fund-raising so that research can aCComplish great things in the future.

CC Day 9 - Sharon Solomon

After having the whole of the right side of my Liver removed in April 2011 at the age of 42 due to Cholangiocarcinoma (CC) my life has been upside down!

After my operation I was asked if I would join the Bilcap Trial, so I started researching CC more and that is when I found AMMF and Helen Morement. After contact from Helen I made the choice of going onto the trial and was chosen to be on the Observation part of the trial which is great as I have scans and tests more often, lucky for me one of these scans showed a nodule on my lung which I am now undergoing more tests for!

It is amazing how life changes, you always think it will happen to others but not to you or your family, but it does! And there are more and more people diagnosed each year, please will each and every one of you support AMMF in any way you can, they need all the support they can get to help raise awareness of CC!

If I did not have the love and support of my husband Ronnie and our beautiful children, our gorgeous granddaughter Lexie, and my loving Mum and Dad, cousin Maryann Williamson and all my amazing friends, Marina King and all the rest of my friends, I don't know how I would have made it through it so far!

Helen Morement - I would like to say a huge Thank You to you for all the love and support that you and AMMF give to each and every one of us. You are an amazing lady!!!!

Thank you to all of you! xxxxxx

CC Day 10 - Joan McAuliffe (California)

February is cholangiocarcinoma awareness month. Despite much progress in the treatment of cancer, only 5% of those diagnosed with CC are likely to live beyond a year.

My dear friend, Alan Morement lost his battle with this disease in the year 2000. His greatest wish was that more research would go into the possible prevention, education, and successful treatment of CC. His wife Helen, at AMMF, has dedicated this past 12 yrs to this cause in Alan's name. Much progress has been made but there is still much to discover.

Alan, you are so missed, but thanks to lots of work and dedication by many, your name is on the lips and heart of every newly diagnosed patient. Here in California, I salute these efforts and continue to support Alan's dream.

Thank You xx

CC Day 11 - Chris Allum

My father, Charlie Allum was diagnosed with CC in November 2009 and after he fought the illness so hard he passed away peacefully on 12th June 2011, a day that will live in our memory forever.__

Now I look back it amazes me how quickly this awful disease took a grip of my healthy strong father, without any warning he suddenly fell ill with the symptoms that everyone has mentioned in previous posts. We are forever grateful for the speed with which the Churchill Hospital in Headington, Oxford acted after dad was diagnosed. Dad went through the Whipple procedure and subsequent chemo but CC returned. The full details of my story are contained within my Challenge blog that I mention later in this post.

I became aware of AMMF in early 2010 through my Sister, Nicola Othmani who got in contact with Helen in regards to raising money for the charity through a Slimathon which has been a massive success, seeing her raise over £2000 so far for AMMF!

As you grow up you always expect to have to go through the pain of losing your parents, but this is not something that I expected to do at 30 years of age when my dad was just 55 years old. Our dad is a massive inspiration to us all, the way that he battled this illness and shielded the family from the pain that he was going through and remaining positive whilst being thankful for every day he had throughout the illness. We have a massively strong family, a characteristic instilled from dad, the head of our family and we are pulling together to get through these dark times.

Nearly 8 months has passed since losing dad and I still think about him every day but I hope by living my life to the full and ensuring I achieve all my goals I will honour him in all I do.

The work that Helen and everyone involved with AMMF do to raise awareness for this little known disease, known as CC, is fantastic and cannot be underestimated. As has been said in other posts the key is further awareness of CC and early diagnosis, if this can be done then we hope that more people can be cured and that other families will not have to suffer further heartache.

For obvious reasons AMMF have become my families chosen charity and like my sister, I too have set myself a challenge which is also a lifetime ambition of mine, I have been lucky enough to gain a place in the Virgin London Marathon on 22nd April 2012. Please take the time to read my blog through the attached link on my JustGiving page and maybe even keep tabs on my progress over the coming weeks of gruelling training! All proceeds will be going to AMMF and, of course, any donations would be greatly appreciated as too would you sharing the link and my story below to your own friends on Facebook. I hope my post gives everyone a further insight into CC and how it has affected me and my family.

<http://www.justgiving.com/Chris-Allum>

CC Day 12 - David Armstrong (Northern Ireland)

My brother Peter was 43 when he was diagnosed with CC in November 2010. Prior to his admission into hospital he'd been feeling generally unwell; out of breath, weak, and had developed a pain in his side. Weight loss had altered his appearance. Initially he was in hospital (Royal Victoria Hospital - Belfast) for just over two weeks and right up to his diagnosis we were thinking, he's in the right place and they'll be able to perform an operation to help him.

After his diagnosis I naturally tried to find out more about cholangiocarcinoma to see what could be done but everywhere I looked had the same devastating prognosis: there was nothing that could be done. Peter sadly passed away 9 months later, on 19th August 2011.

For more information about Peter please look at his JustGiving page
<http://www.justgiving.com/Peter-Armstrong>

CC is such a ruthless disease and so little is currently know about it. Early diagnosis is very important, but at the moment is very difficult to detect. Helen and everyone involved in AMMF are doing fantastic work to increase awareness of CC and raise funds for research so that early diagnosis becomes a reality.

Peter had loved music and used to play percussion in a band with his friends. A tribute gig was held in December 2011 in the local pub where he used to socialise. Many of his friends were there to enjoy the music by a variety of bands and the night was a great success; there was even a live link so friends living abroad (U.S.A., New Zealand) could enjoy the proceedings. Money was raised for AMMF that night and more music events are in the pipeline for 2012.

A cycle CChallenge is being organised and will be held on 12th May 2012, which would have been Peter's 45th birthday. The challenge is to cycle from Whitehead to Ballygally and back and all proceeds will go to AMMF. There will be more details to come. Thank you. David Armstrong

CC Day 13 - Marcella Smith

Well we hear so often Thirteen unlucky for some. 'Unlucky for some' could also apply to our cc family. However, alarmingly cholangiocarcinoma is on the increase. Reading all the posts and listening to all the radio interviews, for the most part, our journeys are all the same; carers and patients feeling shock and disbelief and wanting to receive good news and to have hope.

My experience was full of shock, bad news and ultimately much sadness as my husband lost his battle with cc on the 5th September 2011. During my most desperate times (and there were many) whilst he was ill and after his passing, I always arrive at the same conclusion; however sad it is and however bad I have felt, I have absolutely no control over cholangiocarcinoma and the only thing that I can do is to support AMMF to raise awareness, raise funding so that more research can be done which will hopefully lead to early diagnosis and better treatment. I know that you are all doing the same. I thank you all and AMMF and together will strive to make a difference.

I write this in memory of my loving and fantastic Husband, Stewart who I miss every single day.

Marcella Smith

CC Day 14 - Valentine's Day - George Melvin

Carol Melvin 25.05.1968 - 19.12.2010

Now that she's back in the atmosphere
With drops of Jupiter in her hair,
She acts like summer and walks like rain
Reminds me that there's time to change,
Since the return from her stay on the moon
She listens like spring and she talks like June,

Tell me did you sail across the sun
Did you make it to the Milky Way to see the lights all faded
Tell me, did you fall from a shooting star
One without a permanent scar
And did you miss me while you were looking for yourself out there....

Now that she's back from that soul vacation
Tracing her way through the constellation,
She checks out Mozart while she does tae-bo
Reminds me that there's room to grow,

Now that she's back in the atmosphere
I'm afraid that she might think of me as plain ol' Jane
Told a story about a man who is too afraid to fly so he never did land

Tell me did the wind sweep you off your feet
Did you finally get the chance to dance along the light of day
And head back to the Milky Way
And tell me, did Venus blow your mind
Was it everything you wanted to find
And did you miss me while you were looking for yourself out there.....

Happy Valentines Day sweetheart ...

<http://www.youtube.com/watch?v=7Xf-Lesrkuc&ob=av2e>

CC Day 15 - Nicola Orthmani

A loving daughter's CC journey from right by her Father's side from beginning to a devastating end...

The best Dad a girl could ever dream of -

Charlie Allum 05.11.55 - 12.06.11

Forever in our hearts - Loved and missed so very much.

To read the full text for this post, go to:

<http://www.ammf.org.uk/2012/02/15/nicolas-tribute>

CC Day 16 - Jane Gyamfi-Sarkodie

I met a friend on the London underground this week. We began chatting, and she mentioned that someone she knew had 'a rare form of cancer'. It was cancer of the bile duct, she said, and the outlook wasn't good. Well, although cholangiocarcinoma is still relatively unknown, it is no longer such a rare disease.

This month it is heartbreaking to read the accounts of families affected by CC on the AMMF facebook page, but also heartening to read of the wonderful work being done. Information is made available, research is pursued, and money is being raised.

We often read about the 'battle against cancer', as though it is something that the person experiencing the disease wins or loses. I don't see it that way. If there is a battle, then it involves all of us. The ways in which we support all those affected by cancer, the time and energy we give to charities like AMMF, and the money that we help to raise are our weapons against the disease.

I've known Helen since we were both students at Harlow College. Her beloved husband Alan is the spirit and inspiration behind AMMF. I'm so glad that I can support AMMF - and look forward to a time when cholangiocarcinoma is understood, diagnosed early, and successfully treated.

CC Day 17 - Gillian Corrigan (Florida)

WHEN IT BECOMES PERSONAL

All my adult life I have worked with sick and dying patients and their families but it is a shocker to realise how different the dynamics are when something happens within your own family. I came to understand how important hope and positive attitude really are when faced with adversity and how, like in any stressful situation, people develop strength they never knew they had, be it physical, psychological or spiritual. It is one of the hardest things in the world to do to watch a loved one die knowing that there is nothing you can do to change the outcome.

Watching AMMF grow over the years and seeing the determination of all involved shows how remarkable the true unselfish human spirit is.

I just had a thought --although I can't really participate in any CC challenge this month I have for the past 10 years completed the CCrossing the AtlantiCC Challenge to attend the Summer Balls and CCoffee mornings!!!

(P.S for those not aware I am Helen Morement's sister)

CC Day 18 - Lesley Mercer

My beautiful son, Andrew, aged 32, was diagnosed in March 2004. He was married and a father to a little boy of 3 and a baby girl of 2 months. Despite liver re-section, MRSA and chemo, he was lost to us on 5th March 2006. He fought to the end and amazed his doctors with his stoic attitude.

He was aware of AMMF and requested that we donate to this charity. This rare cancer comes from nowhere and is a huge shock to the sufferer and loved ones. The continuous work of AMMF and research teams, I am sure, in the future will be successful in improving the survival rate, treatment and cure for this rare form of cancer.

It is nearly 6 years since I lost my son... the hardest part is not being able to 'kiss it better'.

I love you Andrew xxx

CC Day 19 - Andrea Fear

In loving memory of my much loved Dad, John "Mac" Clark, who sadly lost his brave and courageous battle with CC, one year ago today.

Dad became jaundiced in February 2010, scarily that was his only symptom and he felt well in himself. After weeks of numerous tests and after being told it was probably gallstones, we were given the news no one wants to hear, "It's cancer, it's called Cholangiocarcinoma and it's inoperable". Our world turned upside down over night. Chemo was Dad's only option but even after 3 stent procedures his bilirubin levels were still too high, and in September 2010 we were told nothing else could be done, Dad had 2-3 months. Even then we never gave up hope, hope was all we had. We travelled to Leeds for a second opinion, but sadly the news was still the same, CC was going to take my precious Dad away from me. Despite all the setbacks Dad never gave up hope, the strength and determination he showed was truly inspirational, he fought till the end. On Saturday 19th February 2011 at 2.45am, Dad passed away peacefully, at home, in the arms of Mom and I. The world has seemed a darker place since and I can't put into words how much I miss him.

When Dad was diagnosed with CC I spent hours searching the internet hoping to find a cure, this is when I found AMMF, the UK's only Charity for CC. In Dad's memory we are raising money to help AMMF carry out essential research into this cruel disease, and hopefully help prevent other families experiencing the heartbreak we, and so many other families have. I'd like to thank everyone who has helped raise money in Dad's memory, I know he would have been overwhelmed by your generosity.

To the world he was one, to us he was the world. We love and miss you more each day xxxxxx

CC Day 20 - Liz Heywood

A tribute to my wonderful Dad, John Smith, who passed away from cc a mere 7 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 just giving page in memory of Dad and in 2012 will 'walk' the race for life again for AMMF!!! (Click the link and see page 4 ...)

http://www.ammf.org.uk/wp-content/uploads/2010/10/AMMF_Winter09_101.pdf

<http://www.justgiving.com/lizheywood-dad>

CC Day 21 - Gavin Strachan (Scotland)

In memory of my dad, Ronald John Strachan 12/7/44 - 10/12/09

My dad was in good health before his diagnosis, fairly active and with no major health issues throughout his life. He had not long stopped working and was looking forward to retirement. A happy soul with a good outlook on life, good sense of humour and teller of bad jokes! He liked his music and played in many local bands throughout his life playing the keyboard. A lot to look forward to and a lot to live for.

Then he got sick in the summer of 2008. His only symptom will be all too aware to so many of you, the jaundice and the yellowing of his eyes and skin. Yellow is not a good colour, I'm sure you will all agree with that! He was admitted to Ninewells and underwent 3 weeks of all the usual tests, ultrasound, CT, MRI, bloods etc. Then we got the news, Cholangiocarcinoma and that it was inoperable. Cholangiowhat? I can still remember the feeling on hearing that, like getting smacked in the head with a bat. Again like all of you, we had never heard of this disease before, what it involved and what it can do. But you hear the words cancer and inoperable and that speaks volumes.

My dad came home from hospital for a week then back in for another 3 weeks for his treatment. He had a metal biliary stent inserted to free up the duct to get the bile flowing, and that helped clear up the jaundice and eliminate the maddening itch. That bl&*\$y itching, grrr..... Then he had Photodynamic Therapy to attack the

tumour. Basically that involves injecting a proformer solution that flows through the body before massing on the tumour. Then the GI doc went in with a laser and zapped the tumour with the hope being that it would shrink. Dad chose PDT over chemo as his treatment as he wanted quality of life for the time he had left and he felt that PDT would be less invasive than the chemo.

By late summer 2009, the tumour started growing again and he was referred to the oncologist to see about starting chemo. But a few days before meeting the onc the jaundice reappeared with some yellowing of dad's eyes. His duct was blocked again so they couldn't do the chemo.

My dad fought a tough fight. He took a lot of knocks along the way but always came back for more. He never gave up hope and was always willing to try something if he thought it would help. And as for trying something, Macmillan organised it for dad to take up horse riding so he learnt how to ride a horse, something that he had always wanted to learn how to do. Sure it would do nothing for his cancer, but it did a hell of a lot of good for his happiness and enjoyment, and it also helped create many happy memories.

I would like to thank Helen and all of those involved with AMMF and the Cholangiocarcinoma Foundation as well. Both organisations do absolutely outstanding work and both are very close to my heart. Together, we will get there.

Gavin

CC Day 22 - Anne Archer (Australia)

At this time last February, 2011, neither I nor those in my circle had ever heard of the word 'Cholangiocarcinoma', nor could we envisage the terrible toll of this devastating disease which just seven weeks later claimed the life of my very dear friend. Nola was not a fan of social media, and I hope and trust that she would forgive me for sharing a brief outline of her story in the interests of helping to spread awareness of the existence of this insidious cancer.

When Nola woke up one morning with jaundice, her doctor was finally given a clue as to the nature of the 'mystery illness' which had defied diagnosis over many consultations. Her experiences in the large public hospital to which she was admitted, here in Melbourne, Australia (one local private specialist was 'all booked up'; the other did not wish to take on her 'case') were, in many instances, and to put it mildly, far from desirable, and recalling that period continues to cause me much anguish on her behalf.

Nola was such a lovely person, a lady in the true sense of the word, a wonderful partner, mother, grandmother, mother-in-law, sister, friend . . . Kind and thoughtful, with an amazing (and sometimes wicked) sense of humour, her life was tragically cut short at the age of 59. She is very sadly missed by all who knew and loved her.

Helen, her family, the AMMF team and all their supporters are to be truly commended for their tireless dedication to the cause of raising funds towards much-needed research (especially in the vital field of early detection), raising awareness of this once rare cancer, providing valuable information and support to those affected, their families and friends, and keeping the public up-to-date with the latest facts and findings. Best wishes to all, and a sincere and heartfelt thankyou from Australia.

Anne

CC Day 23 - Stephanie Corrigan (Florida)

Alan Morement has been a part of my summer for the past ten years through AMMF. I have visited Britain every summer to help out with AMMF events such as the Summer Balls, Coffee Mornings, and even partaking in a 5K run. I also gained some internship experience!

Ironically if my uncle had not died, I would not have seen so much of my UK relatives, but I am proud to be part of AMMF and to have watched it grow over the past decade and to know that it has been so helpful to others.

Stephanie [Alan's Floridian niece]

CC Day 24 - Jason Eastwood

In loving memory of my wife Kelly Eastwood
20/4/1974 - 4/12/2011 Age 37

Wow this is hard, writing a tribute to Kelly that does her justice is an impossible task. She was an unbelievable person that touched the lives of so many even those she only met fleetingly. Adored mum to Emily 11 and Ben 8, the children really were her life, amazing wife and loving daughter and sister. She was also an incredibly loyal and kind friend, it was a massive loss to all those who knew her. Always thinking of others first and doing anything she could to help. The number of people who came up to the family after she passed away telling us what an amazing person she was was touching but not surprising at the same time. __

Kelly's story is similar to most people who have the misfortune to get this terrible cancer. She had a pain in her side and went to the doctors who diagnosed a rib injury. A subsequent visit changed the diagnosis to a muscle strain until she woke up one morning with severe jaundice and was admitted to hospital immediately. Even at this stage none of us thought it could anything too serious and several days later in July 2011 when we were finally told it was cancer it was a complete shock.

I didn't take on board the cholangiocarcinoma part of it at first and just it was somewhere in the liver. It was only when I got home and looked it up on the internet that the severity of the situation hit home. This form of cancer appeared to have a very poor survival rate and even successful treatments didn't seem to match my definition of successful.

From then on I can only describe the next 5 months as a rollercoaster. Knowing that an operation was the only real chance of prolonged survival, initially being told an operation was not possible, to then being told it was, to ultimately being told the cancer had spread so the operation was not an option. Even then we were offered hope with chemotherapy but again this hope was diminished when we were told Kelly was too weak to start it. It is testament to Kelly's strength, courage and determination that she ultimately went on to have several chemotherapy sessions until she passed away in December. In my eyes she didn't lose the battle because it was one that couldn't be won.

The most shocking statistic which I read and was posted earlier this month on this site was that only 5% of people diagnosed with CC survive a year or longer. A shocking statistic confirming the lack of research into what is evidently an increasingly recurring cancer. Kelly was a 37 year old non smoker, non drinker who led a healthy lifestyle. Quite simply the last person you would expect to get any form of cancer, let alone CC. This shows CC shows no prejudice when inflicting itself upon someone whether it be gender or age. Being told initially that it was rare for someone as young as Kelly to get it offered little comfort and based on the many stories on here and other websites, proved to be totally incorrect.

We knew the funeral would be well attended and this brought great comfort to all the family and especially the children. Kelly's mum, who was a rock throughout and never left Kelly's side, suggested we didn't ask people to send flowers but donate to a charity. Having been glued to the internet for the last 5 months I had been a regular visitor to the AMMF website and seen the excellent work they were doing. The site was a source of great information and I can't thank Helen and the rest of the people behind it enough and express my admiration for the work they are doing. The research into trying to find an early detection is invaluable so it was an obvious choice that we set up a Justgiving page. In just over two and a half months the fund has reached over £11,000 pounds thanks to friends and families amazing generosity. Along with all the lovely messages showing just how well thought of Kelly was, this has again proved a massive comfort to all the family. On top of that, the satisfaction of saying that Kelly has helped donate such a significant amount to such a worthwhile cause (which will only increase with the number of fundraising events that have been lined up). If this helps to prevent one person from going through what Kelly had to endure, then I am sure there will be one angel in heaven that will have a smile on her face.

Whilst the pain of Kelly's loss will never go away, helping AMMF to achieve their goals is proving great comfort to all the family. It is exactly what Kelly would have wanted. As Ben said last night, when I'm too old to help the charity he will take over. You have brought them up well Kell and they are a credit to you. It was an honour to be your wife and you will never be forgotten by all those that met you.

Jason xx

http://i1078.photobucket.com/albums/w494/Jason_Eastwood/kell1.jpg

<http://www.justgiving.com/Jason-Eastwood>

CC Day 25 - Helen Tanner

It is now one year almost to the day since I first returned to work (albeit part time initially) following my liver resection for CC in November 2010. Looking back, the year seems to have flown by quickly, but I remember much of it being made up of many small steps - a week, then a month, then another month, never quite daring to plan too far ahead just in case. Getting to one year after surgery was a fantastic feeling - a milestone I couldn't even consider reaching earlier in the year.

Now the steps are a bit bigger - a year since I went back to work, then the next one to aim for is 18 months since the surgery and then we'll see what comes after that.

CC creeps up on us unawares, and I know all the statistics by heart. I know that I am, for now, one of the lucky ones, but we desperately need more research into CC, and in particular to ways of diagnosing it earlier when surgery is more likely to be possible.

It is only through AMMF and the hard work by Helen and all you lovely supporters that this is going to happen, so keep up the great work - we need you.

In the meantime, I have just had the "all clear" following a recent scan and my lovely hubby and I are off on holiday in a few weeks....!

Helen x

CC Day 26 - Jane Cooper & Emma Wilson

A year ago today mum (Jenny Vaughan) was admitted to hospital with such severe symptoms that within 5 days she was told that she was so advanced with cholangiocarcinoma, there was little that could be done. Mum died on March 9th 2011.

Mum first had problems with her Cbd in her 20's which we have found out subsequently caused the cc. However we are grateful mum then had another 30 years leading a full and active life with dad and us. The past year has been extremely hard and we all try hard to focus on the positive memories.

AMMF and Helen have been a vital component in helping us move forward and we pray other families may be prevented from losing a loved one in this way.

Jane Cooper and Emma Wilson-Pulley

CC Day 27 - Jessica McMullen

My Beautiful Mum was diagnosed with CC in December 2010 when my partner and I were living in Cornwall. We had no idea what was ahead of us and although I had done lots of reading I still hadn't come across AMMF. I wish I had as nobody else has heard of CC including our Macmillan nurse, or any of the nurses we met at the hospital for that matter.

When Mum was rushed in to intensive care in January with septicaemia I had to drive 300 miles at 2am fearing the whole way I wouldn't make it in time to see my Mum again and give her a big hug. Luckily that time she made a good recovery, but it weakened her greatly and the positive outlook for an operation and chemo suddenly dwindled. I couldn't stand being away from her so we moved our whole life back to Nottingham and I spent all the time I had with Mum.

She had numerous stents which would not last long before they were blocked again and she kept positive till the end, practically begging the Doctors to give her some chemo and making the nurses laugh, but the bilirubin was always too high. She passed away 7 months later on 2nd July 2011.

She always said she wanted to help other CC sufferers and we had signed up for the Race for Life with our family and friends later that month, although she would have to be in a wheelchair. My heart goes out to the AMMF family this month and their fantastic work.

My Mum and Dad would also have celebrated their 29th wedding anniversary yesterday and so this song is for a very special wife.

Happy Birthday Mummy you are always with us and we love you more than we ever got to tell you but I am saving an extra big hug for you. xxx

<http://www.justgiving.com/Tina-Elizabeth-McMullen>

http://www.youtube.com/watch?v=-_UwU-RRqSE

CC Day 28 - Jo Wapshott

I first became aware of CC in 2009 when my friend, Helen Smith, was diagnosed. I had never heard of CC before and, if I'm honest, I was surprised that there were still different types of cancers that were not well known or understood. Like others whose stories have been shared via AMMF this month, Helen's diagnosis was too late to be curable and we sadly lost her in October 2010, at just 35 years of age.

Throughout her illness, Helen remained positive and was tireless in her search for treatments and clinical trials that would give her more time with her husband and young daughter. And so it is for this reason that my friends and I support AMMF, so that the search for more effective treatments and hopefully a cure for this disease can be found. And we will continue to support AMMF in memory of our very brave friend and in the hope that other young women, like us, will not have to lose one of the girls.

In June we will be once again running the 10k Race for Life along Bournemouth seafront. If you would like to sponsor us, please visit our JustGiving page at:

<http://www.justgiving.com/TheReturnOfThePinkPanters>

CC Day 29 - Julia Wise

Feb 29 - A RARE DAY IN A RARE MONTH FOR A RARE CANCER

I went to have a blood test the other day and the nurse asked me about my wristbands and the significance of the tree symbol. I told her that my sister has a very rare cancer, called Cholangiocarcinoma, and that no one's ever heard of it. She said, "I'm in the medical profession and I've never heard of it."

I'd never heard of it either, until 31st August 2009. Even then, I didn't hear the name; I read it. Susan had been allowed home from hospital on a 24-hour pass.

Sounds generous, but being a Bank Holiday, all specialist meetings at the hospital had been cancelled and there were no further tests they could carry out on Susan until the specialist teams from Kings and St Thomas' Hospitals had met to discuss her.

I read her day-release form and it said Cholangiocarcinoma in the "reason for admission" box. That was the first I'd heard of it. Until then we'd constantly been told "we don't know" when we asked what on earth was causing Susan to become jaundiced and to scratch her legs until the blood ran. I went and looked it up on Google. Big mistake!! Until I found the Cholangiocarcinoma Foundation in Salt Lake City, every site I looked at was terrifying, bleak and simply made me feel worse (I didn't find AMMF until quite a bit later).

Through CCF, I made some wonderful friends all over the world. The first UK-based friend who reached out to me was the gloriously vibrant and ever optimistic Val Mutton. I was also lucky enough to meet Liz Heywood, Andrea Fear, Gavin Strachan, Pauline Roberts and Helen Morement through CCF and, through Helen, I discovered AMMF. I am now fundraising for AMMF and campaigning for greater awareness. I don't want anyone ever again to say they've never heard of it or to read out-of-date statistics or to feel so alone, as my family and I did when Susan was diagnosed ...

... But let me tell you about the lovely Val Mutton:

Val emailed me one day and told me she was coming to London for her 50th birthday, so we arranged to meet at Covent Garden and that's where I first encountered the bundle of energy who, until then, had simply been an online username to me (Valjee from Cornwall, UK)

We had a wonderful day and I was amazed and delighted to be invited to join her and her brother for her 50th birthday meal (cocktails at The Ivy, followed by a meal at Scott's in Mayfair). I had such a marvellous time and Val became a very dear friend, by text, phone and email. She was constantly making plans to visit again but the snows prevented that and, by the time the weather stabilised, Val's health was deteriorating.

She had originally been told her cc had been found very early and that the surgery had completely removed it. No chemo was considered necessary; she was "cured". She had awful after-effects from the surgery and it appeared scar-tissue was starting to block the ducts (to me, aspects of the "cure" sounded worse than the disease). She went into Total Organ Failure in April last year and was resuscitated. She was then told she could either stay on an external drain for the rest of her life "which probably wouldn't be long" or have further surgery, which would give her a "relatively normal" life, but which she may not survive. Ever both optimistic and practical, she hoped for the best and planned for the worst. She had the surgery in November last year. She didn't survive it.

Her brother called me to give me the news and told me she had left a notepad on her bedside cabinet when she went into the operating theatre. They looked at it after she died and it contained "6 numbers to call if I don't come through the operation"; mine was one of them.

I couldn't go to her funeral but her mother sent me the Order of Service and thanked me for being such a good friend over the past 2 years. Dear Val - I thank YOU with all my heart. I would have totally lost all humour and perspective if it hadn't been for you. I miss you and your outrageous sense of humour so much.

If you can help us help AMMF, please visit:

www.justgiving.com/cholangiocarcinoma

or

www.justgiving.com/bileductcancer