‘My story’ transcripts selection from the old Forum (called Meeting Space) –edited

Years 2011 -2010

Note: The value of these stories lies in what can be learned from one person’s story and applied to benefit others. Not all are happy stories – some are about those who have died from CUP as well as those that have lived (either with a CUP diagnosis or with a site specific diagnosis) but all say something about CUP and its impact, its treatment etc.

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Chemo Update *Posted on:* November 29th, 2011 *by* Cheryl

After an successful start to the chemo (30% reduction after 6 weeks) we have had bad news at the end of the 4 months. The cancer has already started regrowing and is almost back to where we began Maybe I'm fooling myself (but I need some hope)… During the first 6 weeks I was following the Budwig diet but was then told to stop it as it was very high in Omega 3 and this could stop the Cisplatin (chemo) getting into the cells. Interestingly I also had very few side effects of the chemo whilst on the diet eg no hair fell out until I stopped it!I did continue to use flaxseed oil as a rub, but did not do it every dfay. My undertstanding was that the cancer was still in the right of my abdomen so I was focussing there. Interestingly, these tumors have not grown! The otehrs have… Now that I know where they are I am oiling all over. I have also restarted the Budwig diet so fingers and toes crossed. If you're interested you can look at budwig-videos.com. There's a forum you can join which has many many testimonials. Budwig herself claimed 90% success rate in taking terminal patients from hospices. There is also a hospital in Germany specialising in this – 3E. I don't have a date for my next scan but will ask for one in 3 months and will post the results. I'm hoping to feel some results before that though.

> Cheryl I always think of the Serban Scheriber view:
> 'In a domain like oncology two things are continuously changing: conventional treatment and our knowledge of what each of us can do …to reinforce the effect of these treatments.' As Sallie says we have to keep on and pursue all avenues.
> Love Peter *Peter MAc* says on November 30, 2011 at 7:59 pm

cup one trial *Posted on:* November 19th, 2011 *by* lisarore

Hi i was wondering how many of you have been on the cup one trial? if so any side effects you can tell me about, The reason I ask is my mum (hazy) has had so much swelling and blockages and blood clots over the last 6 weeks that she has went from happy confident and fighting to depressed and disabled she is unrecognisable and the doctors have now told her to come of the trial was wondering if anyone else had these symptoms or others????????

> Hi LisaI don't want to preach but have you looked into diet? There's been quite a bit done that shows a vegan diet with no glucose or white carbs can cure … I'm personally an advocate of johanna budwig's diet but it's too early for me to report if it's working. I will keep posting though. Food for thought, literally!I found the diet really limited the chemo side effects and I got good results at my first scan (better than onc. was expecting) which I put down to the diet too. I hope your mum's health and state of mind improve soon, I also hope the cup one chemo works for her. Your mum is not alone in her fight – we're out here fighting too. We need to help each other battle it and prove the docs wrong. Xx*Cheryl* says on November 20, 2011 at 10:41 am
>
> Hi lisa I've also mailed you and suggested you send your query on the CUP trial to the 'Contact Us' section of this webiste. I've found it useful.I would agree with Cheryl I think diet can help. We also do 'Mindfulness' exercises to help us cope with the stress, tension and pain. Look up John Kabat Zinn on google or Amazon for the books.Best wihses and hope this info helps Peter*Peter MAc* says on November 20, 2011 at 11:37 am
>
> Lisa – very sorry to hear of these distressing side effects. I asked the CUP-One team for a comment and one of the oncologists has responded – see below. I shall be interested to know if you received a patient information sheet and have an allocated nurse or key worker. "The CUP-ONE chemotherapy treatment called 'ECX' has been in use for CUP for more than 20 years (and is also used routinely in stomach cancer) This should be explained in the patient information sheets that you should have a copy of. For the distressing symptoms- this should be discussed in detail with the doctors and nurses in detail to see how these can be improved (it is often helpful for a relative or friend to be present) All chemotherapy, whether on trial or standard, can be discontinued if the patient or medical team do not think the patient is benefiting or having too many side-effects affecting the equality of life. It is sometimes very difficult to tell how many and which problems in advanced cancer are due to the cancer itself or the treatment – and this should be discussed in detail with the medical team Your mum should have a direct contact to either the research nurse (on the consent form or Patient info sheet usually) or a nurse-paractictioner (also called CNS or ANP) it would be useful to discuss these concerns on the telephone with them in advance of the next consultation " *John (Moderator)* says on November 23, 2011 at 5:56 pm

Chemo Treatment Unsure ***Posted on:* November 16th, 2011 *by* Peter MAc**

My wife has undergone Chemo for CUP for the last three months. Epirubicin, Cysplatin and Capacetibine. The CT Scan results showed that the cancer has not grown but has not reduced either since the last CT scan in August The Oncologist is examining the results further but has indicated that he may conclude that the chemotherapy is not working -rather its the cancer that is slow growing. He has stated that he does not see an alternative if it is agreed to end the chemo treatment. We are having the Lab 21 test carried out to give us further information and having a second opinion referral froma CUP specialist. Not sure if there are any words of comfort but we're trying to deal with it. WE're seeing the Onc on Monday next.

> Every cancer is individual and unique. I was diagnosed with CUPS in Dec. "08. Treated with cisplatin and gem-side-a-bean (phonetic). I responded quickly, getting 75% reduction in tumors and then no sign of them. I have been tumor free on CT scans, which Ihave. *balar53* says on November 17, 2011 at 2:00 am
>
> Many many thanks again we have been beavering away with the support of comments such as yours and others on the Mutual Support/Medical Advisers section of this website. Our (Mel's) Oncologist also contacted us today stating that the cancer blood markers from the test on Wed showed improvement and were down-so,on the basis of existing evidence, he felt that the current treatment should continue-at least through the next cycle. He's also progressing with the Lab 21 test -hopefully on the material from the biopsy in August.So many many thanks again-This website and the mutual support within it so important and valuable*Peter MAc* says on November 18, 2011 at 9:25 pm

> Hi peter, my mum (HAZY) has just been told the chemo is not working also, her masses in the lymph nodes have grown which is very disappointing but we are going to have a chat with onc on Mon or Tue next week, she is currently in the hospital with a collapsed lung which has been caused by swelling and clots!!! she has not had the best couple of weeks to say the least, going from confident and high spirirted to depressed and unable to walk in a matter of weeks, if we could reduce the swelling and blockages i am sure the chemo would at least have a chance as its not getting to flow round her body at the moment, has Mel been on the cup1 trial? as we think this is the crux of all the probs and she has been taken off it now. I hope lab 21 helps that is our next step too.Keep us informed coz its great to hear everyones progress from time to timebest wishes lisa*lisarore* says on November 19, 2011 at 8:22 pm
>
> Hi Lisa I've sent you a reply directly to your email as well.Mel is not on the CUP trial but is on the similar chemo package as the trial. There is detail about the trial in the research section of this website.But in seeking more information about your Mum's situation and the CUP trial you may find value in clicking Contact Us on the home web page (top right) and leaving your query on the email fomr that posp up. I have used this and have found it extremely useful-I'll rephrase that I've founb it unbelievably helpfulKeep in touch *Peter MAc* says on November 20, 2011 at 11:29 am

afraid of the unknown *Posted on:* October 21st, 2011 *by* annieoo

i am a 59 year old woman who was diagnosed with cup in 2010. underwent 8 treatments of taxol and carboplatin. last treatment was in march. now i have two enlarged lymphnodes under left arm and am having lymphnode dissection next friday. my prognosis said that i had an excellent response to the chemotherapy. if so why do i have these two cancerous lympnodes?? i am so depressed i dont know what to do. oncologist said that i would probably have to have 4 more chemos and that awful neulasta shot!

> Hi Annie What is a lymphnode dissection? Are they removing them? If so…hopefully that'll get rid of the cancer (I like to assume that my immune system killed off the primary therefore I'm only dealing with the secondary).What % reduction did you get with the chemo? After 4 treatments I had 30% and have my next scan on 21/11 so I'm hoping for a lot more. We're all terrified out here – try to take some comfort in the fact you're not alone and that docs are wrong all the time. As CUP covers all types of cancer all over the body the stats are very vague and inaccurate. Let us know how you get on x *Cheryl* says on October 25, 2011 at 11:19 am
>
> Hello Annie I was diagnosed with CUP 2007 and had the Taxol/ carbo treatment along with etoposide. I still feel that I'm like a flamingo – wating for the other foot to drop. In the meantime I decided to live life and smell the flowers.My oncologist speculated that the primary was microscopic and was killed off or killed itself. I found this site by accident after I finished my chemo and have been a faithful reader ever since. I still try to explain to others what CUP is. I still keep rooting for others & let them know I'm there even though I over here in Canada.Dianne *Arcticnurse* says on October 29, 2011 at 5:37 pm

Glad that I have found you all :) here is my cancer tale *Posted on:* October 14th, 2011 *by* bonch

I haven't got all the dates (my mum has) I'm not an anniversary kind of gal!! In May of this year, my ex husband (dad of my 13 year old son) died suddenly from a massive heart attack (47 years old) RIP Bri. As you can imagine it was a very stressful time and a couple of weeks later I noticed a swollen gland in my left armpit (or axilla I think is the medical term, I'm not very good with medical terms either and tend to make up words that sound like the actual) I put it down to stress and got on with it. About 4 weeks later I was woken in the night by a painful throbbing feeling in my armpit, I didn't really think much about it again. 2 weeks after that it happened again and that's when the lightbulb above my head pinged and I thought omg that pesky lump has been there all along and is shouting to me “I’m still here, check me out” I then made an appointment with my gp and at the end of June I saw a locum who prescribed me antibiotics but insisted that I return in a week regardless of whether the lump had gone. This I did and when I returned I saw a young female gp who was covering maternity leave, she examined me and diagnosed a reactive lymph node which didnt need referal even though I had advised her that my dad died aged 60 from non-hodgkins lymphona. To cut a long story short I returned twice more to be refused referal until a breast surgeon friend of mine urged me to seek a second opinion which I did and was referred under the 2 week rule to the breast clinic. That was on a monday and my appointment was on the thursday of the same week, I was asked to return to hospital the next morning to have a biopsy of the lymph node and the week after I met with the consultant who told me that there was cancer in the lymph node. This was a massive shock as the original gp had made me feel like a right moidering hypochondriac and I was originally going to go for the results on my own until my mum insisted on coming with me. I then started to have tests fine needle biopsies, ct scans, mri scans etc and awaited the results. I met with my consultant who told me that the scans hadn’t shown cancer in the blood or bones and the suggestion was to have the remaining lymph nodes removed and 6 months chemo with a possibility of 3 weeks radiotherapy after this I was told that there would be a 15% chance of cancer reoccuring in the left breast and was offered a mastectomyas well. This I went for. I have recovered exceptionally well from the surgery (model patient and can come back anytime according to the ward sister) The cancer has not been found in the breast or in any of the other 14 lymph nodes which the surgeon was really pleased about. The letter to my gp stated that no primary cancer has been found even though a few further levels have been examined by the histopathologist. The lymph tumour was ER positive, PR negative, HER2 positive. I do not require radiotherapy but need 6 months chemo, 12 months herceptin and endocrine therapy. Most of my family and friends are very happy with this outcome and consider me cured (albeit pending treatment) myself however, whilst pleased, have a little sinky feeling in my chest when I think that the primary could still be in here somewhere. Do do do do do and muahaa ha ha ha!!! Thoughts please from people who have been there, thanks for listening xx

Hazy *Posted on:* October 13th, 2011 *by* Hazy

Hi My name is Hazel Rore age 54 – Lisa Rore’s mum who first wrote about me on here. I have CUP cancer and I am actually very positive about it. Although I don’t know where my cancer is I do not feel unwell nor do I fear that I am dying. I have wonderful support from my family and freinds as I am sure most of us do and they too are very positive and upbeat about the whole situation. The hardest part is the unknown with CUP I have inquired through my consultant to investigate Lab 21 and although happy to do so she worried that NHS would not pay for any drugs if the primary was found – but still happy to proceed with a full investigation and recommend yes or no to following that path. When I was told I had cancer I became depressed – don’t we all???? I lay about feeling sorry for myself wondering how long I had left in this life – a good life a happy life a content life!!! Things changed when I went through my first Chemo – my energy levels improved 10 fold – I could do anything – I got up early morning showered dressed shopped cooked cleaned socialize and began to live life to the full again – I am still the same today – not prepared to give in to anything! What is the point it is not going to change anything and I certainly feel alive again – yes I do get tired but nothing half an hour on the sofa wont fix! My partner and daughters and their families are fantastic – we do so much together and really live for the moment they help me round the house we do lunch we shop we laugh we live!!! Sorry is this is a bit flippant but it is how I feel and if I manage to reach the age of 60 I will be over the moon. Yes it would be nice to havve some answers and maybee one day I will have – but till then I just have to keep moving on with what I have. Regards Hazy x

> Hazy-it is good to read that you are responding so positively and feeling so positive.
> Mel, my wife is into her second cycle of chemo and similarly, apart from one or two glicks, the chemo has so far gone ok and we are keeping positive. We go for a walk most days and Mel meeting her friends for lunch.As you say the most difficult element with CUP is the unknown. Our oncologist belives it emanates from the upper bowel and has devised the chemo to zap that. Mel’s decided to hold back on Lab 21 for the moment to see how the chemo is working. As Cheryl says- good luck and keep updating Best wishesPeter *Peter MAc* says on October 14, 2011 at 6:03 pm

> Hi Hazywonderful to see your sense of humour bubbling up through the chemicals. I'm 55 and am also shooting for 60, so we have something in common. Not the cleaning however. No amount of life-threatening illness will make me want to get up and clean. Cook maybe. Clean? never!Hang in there. Somebody has to beat the odds. It may as well be you and me.margo*ShovelWhenItSnows* says on October 15, 2011 at 4:35 am
>
> Hi Hazy We've found that having the wig shaped by someone who knows how to cut wigs helps and Mel is now confident wearing her wig with scarves and hats. Her NHS wig is actually very good. She's also bought some hats and scarves from Accesorize which she wears with the wig. The following websites may be of use:
> http://www.bohemia-fashions.co.uk
> http://www.randrconfidence.co.uk and
> http://www.annabandana.co.uk
> These were suggested to us by volunteers at our cancer centre who help with suggestions for tying scarves etc. Hope this helps Peter *Peter MAc* says on October 21, 2011 at 6:30 pm

Young mother *Posted on:* October 12th, 2011 *by* abrea

The very hour I left my oncologist office I called back to his office. It was closed! I left a message apologizing for what happened. I was urged by my mother and husband to beg him to help me! So I did! Only to get a call from his nurse to say that he still wanted me to get a second opinion and see another oncologist I'n his office! The surgeon is specialized I'n whipple procedure but not a cancer doc! His nurse was polite! I'm seeing them Friday! And as far as the oncologist I'n dr canters office! Well I don't want them at all! I listened to the recording of that visit over and over! I would rather be so sick and have someone genuinely care and want to be my doctor than someone who doesn't! It's most important to have quality! I was to much of a challenge!

my mum's story so far *Posted on:* September 22nd, 2011 *by* lisarore

Hi i am new to the site but so glad i found it. My mum has just been diagnosed with CUP, her symptoms started with weight loss, 2 stone in 2 months, then she discovered a lump in the side of her neck she went to doc's who thought at first it was some sort of lymphoma. this was devestating enough, but at least we knew what we would be dealing with we researched and educated ourselves. then the biopsy showed no lymphoma and her oncologist said it was likley to be a cancer in the lining of her pancreas or lining of small intestine, but as it was so small it did not show on the scan so could not operate and her primary cancer would prob never be found. How can this be ???? in this day and age, i just dont understand, they have not gave ANY prognosis whatsoever, so we are entering this blind and very scared. Mum started chemo today ……….so the journey begins.

> Hello I went through a similar reaction three years ago. "They can send a man.woman to the space station but they cannot find OUR primary I say "OUR" because we are a unique group people. Te chemo is tough, physically and psychologically.Just be there to support her. My rock was my husband of 45 years and my adult children. You'll know within a few sessions (chemo) if they are on the right trackI'll be thinking about both of you. It is now 4 years since I was told the diagnosis. My life has changed for the better. Dianne *Arcticnurse* says on September 24, 2011 at 3:09 am
>
> Lisa you may also want to look at the option of gene profiling testing for CUP that is mentioned in this site (look in this site under: diagnosis and treatment/special tests). The tests seek to use gene profiling to dentify the primary cancer characetristics and assist in defining the chemo tretament. An English company Lab 21 offer this service at a cost. We have not used it but there are several people with CUP who use this website who have emailed to say it has helped in defining the chemo

> treatment. As I said our Chemotherapist felt he had identified the source. But we may well still seek to use this test. Peterx *Peter MAc* says on September 25, 2011 at 4:23 pm

The story of a young mother *Posted on:* September 14th, 2011 *by* abrea

I was diagnosed at age 21 I'm now thirty five! I was diagnosed stage 4 back then, I had multiple surgerys! And a liver resection! I'm now very sick agin! It seems the three tumors I have are conected to main body organs! I'm having them removed September 28th I'n just a few weeks! I have so many things on my mind

what would you do? *Posted on:* September 12th, 2011 *by* Janet Gillespie

Hi everyone. My metastic tumour was in my left axillary lymph node. (Removed by surgery Sept 6/11) Many tests have been done, but still no primary tumour found. My questons: Would you have a mastectomy if no primary site was definiteively found?Would you have a small cyst in ovary removed laproscopically if there still is no primary tumour?Would you do chemo and radiation if there is no primary site ? (chemo due to start Sept 20th, radiation to follow)I work in an animal hospital … do you think I could/should work/can work through the chemo and radiation?J

> Hi I had chemo first for my lymph node, no primary was ever found. I had the lymph nodes removed post chemo and then had rads. Im still on Herceptin. It was presumed that the cancer primary was in my breast because of the path report but will never really be known. i was given the choice of masectomy and decided against as if there is nothing there why take it. Its not an easy one to decide but i had all the treatment i could bar the masectomy. Good luck. *sallie* says on September 13, 2011 at 8:07 aps im now in remission. *sallie* says on September 13, 2011 at 8:08 am (Edit)
>
> Lab21 may help find the primary to help with your decision – they take 2 weeks and cost £2,200…I am on cisplatin and gemcitabine so a different combo for a different cancer but certainly wouldn't be able to work. I'm in bed shattered quite a lot ☹I'm 39, not sure if age makes a difference but I believe cisplatin is a very strong chemo. Your oncologist may be able to help with some more info.Sorry you have such a hard decision to make. Chin up and fight …*Cheryl* says on September 13, 2011 at 9:14 am

ECX-chemotherapy-advice needed *Posted on:* September 12th, 2011 *by* willow

Hi I am trying to come to terms with all the bad news that's been thrown at me. I went from being told nothing to being told everything over the course of one week. I was told primary not in my breast plus second tumour in my chest, 1st tumour being found in my neck, then told that they couldn't find primary and I had another tumour in breast gland under arm & 2 more tumours in my stomach.My treatment starts 21/9 its a combination of chemotherapies,called ECX chemotherapy (epirubicin,cisplatin & capecitabine (or Xeloda as it is also known as). The first two are giving intravenously from 8am-7pm every 3 weeks, the 3rd one is given in tablet form twice per day, every day.They are also considering radiotherapy for tumour in neck but feel they have got time to see if chemo will shrink tumour it's 4cmx2cm. I was wondering if anyone has been or is being treated with this chemo regime and if so how you coped or coping with it, also how effective it is. I'm numb, feel like I'm living a nightmare & can't wake up, apart from the anxiety at living this nightmare I look and feel so well. My husband thinks sometimes it's better not to know what the treatment is like but I hate going in blind and feel I'm in more control if I know what I'm facing. Oncologist has given me brochure to read on treatment and I know everyone is different but I feel hearing from someone who has experienced the treatment is much more reliable and I will allow for the fact the chemo reacts differently with each of us. I would greatly appreciate any advice or anything anyone can tell me about this treatment. Thankyou Anne x

> Hi Anne. I’ve been on all those medications (although not all at the same time – in two different courses of chemotherapy which also included gemcitabine and Herceptin – do you know if your tumours showed strong Cerb B2?) and I found it manageable. I was able to work although I worked shorter hours and napped a lot. I think it’s a good idea to take anti-nausea medications before nausea kicks in, so you aren’t always “chasing” the relief. In terms of effectiveness of those treatments, I think they are effective. I had a poor prognosis at the time of my diagnosis and with treatment, I will be three years cancer-free as of November this year (knock wood, fingers crossed and prayers said!). Like Cheryl, I think diet can be helpful but in a nutshell, my approach is just less sugar and more omega-3. Also green tea although I am better at drinking cappuccinos than green tea ☺.
> This is just a chapter. Be glad that you are getting treatment and please let us know how you are doing. I will be thinking of you on 21 September. *kplondon* says on September 13, 2011 at 12:18 pm

> Thanks Kplondon & Cheryl Thank you both for replying, I pray I find the chemo as manageable as you did Kplondon, I don;t know if my tumours showed strong Cerb B2 but will ask tomorrow at the cancer clinic. I’ve had chemo & radiotherapy 6yrs ago for cervical cancer and it was effective in getting rid of the cancer. It wasn’t easy but I coped, this time I’m more scared, partly because having been through it before. I imagine it will be worse this time with three different types. Also I have been told by my oncologist that the cancer I have is adenocarcinoma – glandular and is treatable but not curable. They say that hopefully it will go into remission but for how long they don’t know but that it will come back. I hid most of the symptoms last time from my kids they were 7 & 11 but now they are older 13 & 17 it won’t be as easy to hide the side effects especially as I didn’t lose my hair last time but will this time. The kids know I have cancer, a tumour on my neck but I haven’t told them I have other tumours nor have I told that it isn’t curable, hopefully it will go into remission and they won’t need to know. I’ll take on board what you have both said about diet and research it, it will give me something to focus on other than the chemo.Thank you both again for your advise & kind wishes. Anne x*willow* says on September 13, 2011 at 8:34 pm

My Wife”s Cancer Journey *Posted on:* September 6th, 2011 *by* bewildered

Hi folks, sorry I have not been posting for some time. I have been so busy with my wife going to one hospital or another for many scans etc.What has happened over the last few months is that my wife”s “oncologist” has been as unhelpful, unsympathetic and insensitive as ever. He is basically not interested after giving his diagnosis of my wife having months to live (July 2011).Her respiratory consultant was much more helpful and arranged scans of her brain and bones because of lesions appearing everywhere. We knew the results were not going to be good and the diagnosis came back that she does not have bone cancer but the cancer has now spread to her liver and brain.She is in hospital just now where the prognosis is not good and she is on morphine for the unbearable pain.I think we have pushed every button , followed the rules, knocked every door to no avail.I am sorry to share this news with you all as some of you are doing well, but I felt that i should post to let everyone know that I am still here dealing with the issues we are facing and also to continue my wife”s story.I am hoping that I can stay strong during this very difficult time and in the future hope that I can continue campaigning for more awareness of CUP and general matters relating to chemo, radiotherapy and their sometimes dreadful side effects for some people. Information and research is crucial in understanding any cancer but more so for CUP. Unfortunately, information and genuine feeling in our experience has been woefully inadequate. I may also take up the matter of the shortcomings of some medical staff from the top of the ladder to the bottom and hope to show that patients deserve better. (some of you will have read about these in previous posts) .I will keep in touch and wish all of you the very best. Jim & Betty

> I am sorry to hear about your experience. I hope that you pass your comments on to your oncologist as maybe he/she can learn from this. My first oncologist was very unsympathetic and I know how much additional agony that can cause, which you and your wife clearly do not need at this time. I wish there was a review site for doctors in the UK where we could share this kind of information! I

> wish you all the best and it is heartening to hear how much support you are giving your wife at this time. Katherine *kplondon* says on September 6, 2011 at 11:36 am

CUP *Posted on:* September 5th, 2011 *by* email1999

I was diagnoised with cup Dec.2010. A large tumor was removed from my left groin area. From Dec2010 to March of 2011 I went through every test inside and out. All with the results of negitive! Good news, but at the same time all Dr.'s are telling me stage 4 and I have months to 1yr to live. I have no symptoms, feel very healthy, I work out 5 days a week. Mentally I am burnt though, that's to be expected I guess.When I read the posts on this sight I really haven't found anyone that is similar to my case. It seems like they have been told they have cancer of unknown primary but they have symptoms and there has been cancer found somewhere else even after the first discovery of cancer.I'm hoping that someone will read this and contact me with the same case.I feel my case really is Cancer of Unknown Primary, because it really was only found in a isolated tumor and there is nothing else from the tests and no symptoms.

> Hey Email1999.My case is similar. I was diagnosed with metastatic Squamouos Cell Carcinoma (SCC) of my right ingruinal lymph nodes. I felt great too, working out probably helped me find the lumps in my groin. Had 2 PET/CT scans and all negative. Paps/Colposcopys/colonoscopy all negative. Was treated with a full lymphnode dissection of my Rt groin and followed with full pelvic external radiation and Cisplantin chemo for 6 weeks. That will be 2 years in December and all is good!!Was your cancer SCC?? Stay positive and get lots of opinions.*Patty* says on September 5, 2011 at 9:11 pm

> Just got to hope that your immune system killed the primary and that the docs got the secondary so you're clear and they're wrong! Im guessing they're keeping a close eye on you too. CUP covers all of the body and all types of cancer so stats are rubbish!!! Let'sake our own stats and prove them wrong! Chin up, positive mental attitude helps (along with diet!)*Cheryl* says on September 5, 2011 at 9:54 pm

> Hello 1999. Please read my story, I am a 12 year survivor of CUP, I did not have any symptoms other than what was thought to be a hernia! No primary has been found. I had endless tests, blood, scans etc that all came back negative. You did not say what type of cancer you had, but mine was Squamous cell carcinoma.I am happy to answer any questions you may have, if I can, and hope that you continue to stay strong, focused and well.Take careLyn[Aust]*aussieangel* says on September 6, 2011 at 7:13 am

> I was diagnOsed stage four ten yeArs ago! And since it has sPred to my liver, so I had that removed from my left lobe. I had multiple surgeriesAlong with radiatiOn. I just found out it is I'n my pancreas and stomach I'm gOing for surgery oct 18 the doc wants to do a abdominal resection, and whipple procedure. but yes I was told years ago I only had four years! But that wasnt true!*abrea* says on September 26, 2011 at 3:51 pm

Some info that may be useful…*Posted on:* September 3rd, 2011 *by* Cheryl

Lab 21 may help find your primary – £2,200 but money back if the sample isn't useable. Hospitals know about this but didn't tell me 😕 Top CUP experts are Pavlidis and Greco **Glucose feeds cancer so stop eating sugar NOW**. unpasteurised honey is ok, as is stevia. Docs have knows this for decades and in fact when you have a scan it's glucose they inject you with to show up the cancer cells. Why don't they tell us when we're diagnosed? In the west our bodies are becoming acidic due to processed foods and lack of fruit/veg. Cancer can't survive in an alkaline environment so cut out all processed foods and **go back to nature ie eat what grows out of the ground**. There are many lists on the web telling you what foods are acid and which are alkaline and it's not what you expect eg lemons are very acidic to eat but metabolise to be alkaline so are very good. When you’re alkaline your cells absorb oxygen, and you guessed it…cancer doesn’t like oxygen and dies. Docs know this too…I’m following the Budwig diet (read about it if you want), it’s not the easiest and is very time consuming but seems to work. The main component is flaxseed oil. Very complex unsaturated fat and very high in omega 3 (great for cancer) but in addition it makes you alkaline. The oil thins your blood (good for the risk of DVT if you’re on chemo) and also this means that cells can’t stick together very easily in order to create new tumours.There are lots of testimonals from terminal patients on the forum (start at budwig-videos.com) and Budwig herself claimed to take 1000 terminal patients from hospices and save 90% – she was also nominated for the Nobel Prize 7 times for her work on fats and disease. She discovered unsaturated fats (very very clever woman and way ahead of her time in my opinion but the pharma co’s can’t make money out of food!). My tumors have shrunk more than my oncologist expected so hopefully it’s down to this.Most cancer patients body temp is low which results in all organs, lymphatic system etc not functioning 100% (if you’re on chemo this is even more important as we need to absorb all the nutrients and goodness from our foods to boost our immune system. I’m still researching this one but have found that moxa sticks (chinese medicine) are said to help with this. I’m trying them anyway.There are many many more supplements, diets etc out there but thought I’d share what I’m up to as it seems to be working so far…

Hello *Posted on:* July 28th, 2011 *by* markb

Hi Everyone To be honest I stumbled upon this site whilst trying to some research for a friend of mine who has been diagnosed with CUP during that last couple of weeks.2 months ago he was fine and seemed healthy but has now been told that he has secondary cancer on his abdomen and liver and that the primary cancer is unknown.This week he has started Chemotherapy and has unfortunately reacted badly to the treatment (although I hope he continues with it),I guess really im just here looking for people that can share some positive stories and maybe explain any other treatments, diets, new tests that you have tried.I have found a lot of information on a new test called Cancer-ID test and I wandered if anyone here had used it?ThanksMark

> Hi Mark – I’ll leave others to comment on chemo and treatment, and you’ll find other coments if you go back in the history threads. I guess you’ve seen the information on the gene expression profile tests on our website but I am putting in the link in case you haven’t http://www.cupfoundjo.org/diagnosis_and_treatment/special_tests.html*John (Moderator)* says on August 1, 2011 at 9:59 am
>
> Hi MarkI was diagnosed with CUP “somewhere in my abdomen” I was healthy enough to survive the chemo with all it’s side effects – low platelets.I did end up admitted to for one week. I still have a few other side effects- neuropathy in my feetI happy to say I still here.There is research into CUP in many areas. The most important is the genetic testing of cells. Help your friend remain positive. Dianne*Arcticnurse* says on August 18, 2011 at 2:08 am
>
> Mark I was diagnosed with CUP, secondary in the abdominal lymph glands. I also had a bad reaction to the first chemo (EOX – colorectal) – 10 out of 10 pain for 3.5 hours 😕I was then changed to Cisplatin and Gemcitabine (more gynae related) which was their second choice. Anyway, pleased to say that my body knew best and that I got my first scan results on Wednesday and the tumours are down my a third in 6 weeks. The result was evidently better than my oncologist was expecting. I have to say that I am also following the Budwig diet which I think has contributed hugely too. Docs don’t seem interested though.Lab21 may help you identify the primary – cost £2,200. Unfortunately the last remaining sample of my biopsy wasn’t good enough.Good luck to your friend*Cheryl* says on September 2, 2011 at 9:11 pm

Diagnosed 4 months ago *Posted on:* July 18th, 2011 *by* Beth

Hi, I am an otherwise healthy 57 year old wife and mother who was diagnosed in March with Spine cancer with unknown primary. My only symptoms were lots of pain on my left side for which I was having treatments with the assumption this was a minor back issue. After no relief, an MRI and PET showed a mass that had destroyed my T-11 and T-12 vertebrae and my spine was in danger of immenent collapse. After a 10 hour surgery, I now have rods and pins the length of my spine. This was followed by 28 treatments of high dose radiation at Shands Hospital. There is another spot on my rib that is very small but will be radiated also. Pet scan 2 weeks ago showed no signs of anything else. All I have been told is I will get a PET scan every 3 months and hope for a good outcome. But what's a good outcome? I would rather know where this is coming from I think. Nobody that I talk to has evev heard of this CUP. My friends and family think I had the surgery and the radiation so I'm good. I'm just realizing I'm not good at all and trying not to obsess about it. Should I press my doctors to put me on some of the medications that I've read about? Other than the healing that continues with my back, I feel very good. Should I just enjoy the fact that I do feel good and worry about the probable nastiness to come? Any help or suggestions would be greatly appreciated.

> I am trying the lab21 route to see if they can provide even the teeniest bit more info…I was supposed to have started chemo on Friday but took a horrible reaction so everyone is now back to the drawing board 🙁back in hospital for more tests etc but ultimately it's very clear that they dint haven't seen my type of cancer and don't have a clue what to do or what is causing all my pain. My frustration is mounting. I seemingly only have a few months and wonder if this is how I want to spend them. My baby daughters need me so I have to try everything. It's killing me seeing my friends and family go through this.Sorry it's gone back to me … Keep searching the web and pushing your docs to get more info – we're out here with CUP too so you're not alone. My husband says that there are so few stats on CUP that it makes them meaningless and we need to make our own set … Chin up xxxx*Cheryl* says on July 18, 2011 at 8:44 pm

My Story – so far… (Cheryl) ***Posted on:* July 14th, 2011 *by* Cheryl**

I have had back and stomach pains since march/april and went to my doctors within a couple of weeks. I was referred for an ultrasound where enlarged mesenteric lymph glands were noted. I was then sent for a CT scan – same result, no other findings. Finally a very painful lymph gland biopsy confirmed that I have secondary cancer of the mesenteric lymph glands (undifferentiated carcenoma) with an unknown primary. The doctor was very blunt and said I have 0% chance of survival. I'm 39 and have two daughters – age 1 and 2… this can't be happening.I'm starting chemo tomorrow and have everything crossed that it actually does something. As the primary is unknown they're plumping for lower GI chemo first and if that doesn't work after 6 weeks we'll be changing to gynae. They don't seem to be progressing with investigations to find the primary as they say it won't change anything.I've also looked into diet and it certainly seems to have good reports, the only problem is that I'm very limited it what I can eat just now. Some foods cause me unbelievable pain so I'm sticking to the few I know are ok just now. Hopefully the steriods and chemo shrinking the glands will allow me to eat normally again so I can stick to one of the cancer killing diets. Joanne Budwig gets good reviews but I think there will be a lot of shopping around to find some the of the ingredients.I'm going to find out a bit more about lab21 I've seen on here and I've also got a couple of friends who work in cancer research so fingers, toes etc crossed that they come up trumps.I wish you all luck and please post any little rays of hope/light for the rest of us. I'm not ready to die yet! X

> Hello CherylThe start of chemo is the start of taking some real action to whack this beast upside the head. If they offer you anti-nauseants, don't wait until you feel sick, take them before, they really do work. Good for you for already looking into diet and planning your next steps. Taking charge and taking action helps you feel less like a victim and more pro-active in your own care.After all, you've got a couple of kids who need you when you get better. There are always people who beat odds. Why shouldn't it be you?I'm going to be praying and pulling hard for you behind the scenes. Keep

us posted on your progress and remember we’ve got your back!margo in canada*ShovelWhenItSnows* says on July 15, 2011 at 3:58 am

Hi CherylMy journey started September 2007. Your description of of your assessments brought back many feelings.I too was diagnosed after a painful biopsy of a right inguinal lymph node.A CT scan showed that it also affected all the peritoneal lymph nodes.The chemo they gave me was a combination of Taxol, Carboplatin & etoposide. I was told it was “somewhere in my abdomen”. The treatment was their ‘Best guesstimate” They told if it was working I would know within two treatments. When I questioned the statistics, my oncologist said to me “Remember the stats are other peoples numbers.”it worked. It also changed my life. I now smell the roses, take time to travel to see the grandchildren.I have many people who pray for me. I never considered myself very religious but I have become involved in volunteer work. My thoughts are with you and your little ones.Dianne*Arcticnurse* says on July 15, 2011 at 5:50 am

Dearest Cheryl – even though it is difficult to hear the bad news but you have taken the 1st step well done keep been positive and be strong. I will pray for you dearI have been diagnosed with breath cancer 2005 and my 5th year was on March 2010 and was looking forward the news but, on June 2009 fall and admited hospital and I have been informed that I had cancer in my pelives and it wasn’t related to previous and they called it unknown primary then I took Radio and Chemo and completed on August 2010. Since then, I have been in regular check up and on June 2011, I had CT Scan and it shows that the cancer is back in the same place and in the liver they said it is now unknown secondary. To be honest I am not sure what I can do any more. At the moment I am waiting for biopise hopefull it will tell them some thing. If ANY one have any information for second opinion or any information what can I do please let me know.KD*KD* says on July 15, 2011 at 11:20 pm

CUP people in North West UK*Posted on:* April 28th, 2011 *by* Janet

My CUP diagnosis was arrived at following partial removal of a secondary tumour in my presacral area in May 2010 which involved a bowel resection. This was followed up by 28 sessions of radiotherapy and concurrent chemo using mitomycin and 5FU. The histology indicated squamos cell carcinoma. Following an unacceptable delay, due to informational blockages following a PET and MRI scan, a further site of activity was found. I have just had surgery to remove a further rapidly growing tumour attached to a higher area of my colon and small intestine – a further long op and 3 more resections to my bowel. I am waiting for feedback re histology. Apart from post-op soreness etc. I am generally well. I am supporting myself with the use of prescribed Chinese herbs and acupuncture. I am wondering if there are other CUP folk out there in the NW of the UK who might want to link up? This has felt like a lonely place until I found this site which I am finding very helpful. I was hoping that there might be a newsletter I could sign up for and wonder if one is planned? Best wishes to all, Janet

neck squarmous cell carcinoma *Posted on:* March 10th, 2011 *by* vicki

Hi im vicki from Australia. My story began when my doc noticed a lump in my neck that i didn’t think much about. Doc ordered a blood test, came back ok, then an ultrasound, was ok, then a fine needle byopsi.,,, that was it, lymph node had squarmous cell carcinoma in it,, cancer….When the doc sat me down and told me, i was just beside myself, still am. Anyways after all the tests ct scans, pet scans, they put me in hospital for a comprehensive neck dissection. They took out all lymph nodes on the right side of my neck… soo sore still nearly 2 months on and i can hardly lift my arm up, and numbness, also lip droop, gosh. So they had told me i was to have radiation. Then,,, i felt a lump on my left side just the other day,, they try to do another biopsy but the lumps yes 2, as shown by my ultrasound, were too hard to get too. I jumped off table and now am thinking, well they are just going to zap me with the highest radiation now..Have had the mask made up, and i start next tuesday, 15 March 2011. I am so so scared. What is this crazy thing about cancer that it hides????? If they knew where it was it would be easier to zap. Anyways thanks for listening. I know people out there are going through lots of stuff also. It all helps when you can relate. I hope to let know how it all goes. Vicki. Albion Park n.s.w.

> Hi Vicki – I am on the central coast, nsw and an almost 12 year survivor of CUP. Mine was also Squamous Cell carcinoma, but was in the right inguinal gland in the groin. I had surgery and radiotherapy and had an annual review last week which was all clear. Your friends and family will want to help, but not know how, so tell them what you need. They will look to you for direction. Remember that they too are dealing, in their way, with your diagnosis. Trust your doctors and communicate with them. Dont worry about other peoples reactions to your diagnosis, it usually says more about them than you, you need to channel your energy into getting well. It is worrying when your drs cannot find the primary, but you have to accept the possibility that there may never be an answer. I just tell everyone I am unique and a medical puzzle – usually lightens the moment enough to move on to other things. Dont dwell on it Vicki – just believe that everything is being done for you that is possible, and you are definitely not alone. Stay in touch and I hope that your treatments go well.Lyn*aussieangel* says on April 3, 2011 at 5:40 am
>
> HiI have CUP too, found a lump in my neck last Oct following a sinus infection, 10 weeks of GP appointments led to referral to ENT. Biopsy in Jan revealed squamous cells and CT and PET plus multiple endoscopy examinations, biopsies and EUAs have shown no primary. I had my tonsils removed in Feb, neck dissection in late March 13 affected nodes removed, was told 2 weeks after surgery that I would not be needing radiotherapy but suddenly recalled to the hospital this week via phone message where I was told that I will now need 5 weeks of radiotherapy.
> I had 36 hours of pure mental torture whilst waiting for this weeks appointment as no one would shed any light on why I was asked to attend, I do have a Head and Neck specialist nurse but she was unable/unwilling to shed any light on the subject. The consultation involved the same ENT and Oncologist that gave me the good news about not needing radiotherapy only 2 weeks ago.During the 10 -15 minute consultation I was given the news and asked to sign the consent to treatment…..I had no understanding of the nature of radiotherapy to the head and neck. I gave consent, the side effects described on the form were very brief the oncologist didn't enlarge or provide any detail nor whether the side effects are temporary or permanent, I still have not been given a reason for the contradiction, when I asked why the change of plan I was just told it was the result of a multi-disciplinary meeting and in my best interests, I have not been given the opportunity to consider and to research the subject. Since signing the consent form I have done the research and was horrified at the potential devastation…..on the Macmillan site head and neck radiotherapy patients have endured horrific side effects.I feel so torn as to what to do, I can no longer trust the people dealing with my cancer to be honest with me. How can it change from radiotherapy not being required and for close monitoring to be the plan, to 5 weeks of radiotherapy, it just doesn't add up. How can my 'best interests' be reversed so easily?I truly wish I had ignored the lump…it was painless.Teresa*Teresa* says on April 25, 2011 at 6:07 am
>
> hi John I spoke to the Macmillan helpline earlier today and got quite a lot of helpful advice such as seeking another meeting with the members of the team to clarify the rather vague information that they did give meand to have my concerns addressed, we also discussed going about getting a second opinion, and what treatment options would be left for if and when a primary does show Unfortunately I have been unable to speak to my specialist nurse I left a message but when she didn't get back to me I have left another message which according to her voice mail she will pick up tomorrow. If I don't hear from her tomorrow I shall try to arrange something via my ENT consultants secretary…..and if that fails I shall ask my GP about help to arrange a second opinion. I find it so frustrating that admidst my current dilema I am still not being heard!I had hoped that by today I would be making some progress toward a clearer understanding but instead find myself returning to the angry nauseated stage I was in immediately following the consultation, still at this rate there won't be enough of me to radiate!!Thanks for your reply John it is really comforting to know there are others in similar situations.Teresa*Teresa* says on April 26, 2011 at 5:26 pm

new diagnosis *Posted on:* February 17th, 2011 *by* CarenS

Hi guys, just wanted to let you know that I had a third opinion, and the consultant redid my pathology tests. They have now found serous adenocarcinoma of the ovary! It has taken them 10 months to get the bottom of this, and only through persistence have I found out.I am now awaiting advice as to treatment, but wanted you all to know that maybe further tests can find the primary eventually. Don't give up. There is alo some new genetic testing to find the primary site eg Lab21 (sadly not available on nhs yet though). take care, and wishing you all the best x

> Hi Sallie, I wish you luck. If you google Lab21 it should give you a bit more information, and you can also ask your consultant about it . I do know that they also do this sort of testing in Harley Street. It's quite new and has come over from America. My consultant was going to look into it if the pathology tests came back inconclusive. Keep your head up, and I'll keep fingers crossed. I am continuing with my mistletoe therapy in Kent (which I started in October), and so far I am fit and well with no symptoms and nothing showing on CT scans. I've carried on with my anticancer diet, so I'm not sure what's working but something is. Will see what consultant says on Tuesday as he wants to refer me to relevant consultant to discuss treatment, so here goes….Take care, and hope this helps, Caren x*CarenS* says on February 17, 2011 at 2:25 pm
>
> The cost is £2,200 if you pay for it yourself. I have private health care with saga through AXA and they are trying to say they have never heard of lab 21 and they are not registered with AXA. Lab 21 say they are so interesting argument going on but will get there in the end.*sallie* says on February 18, 2011 at 2:27 pm
>
> This page gives you the detail. http://www.cupfoundjo.org/diagnosis_and … tests.html I have met with Lab 21 and have a contact somewhere if you want me to tell them that they need to sort the registration. It may be that it is registered by product or in the US name? I have had a similar problem with insurance companies who eventually find the details but have got themselves in a muddle. They may require your consultant to say it is necessary.*john symons* says on February 18, 2011 at 2:28 pm
>
> thanks John after battling with Saga all day they say im not covered for it as its an out patient procedure and im only covered for 500.00 I hate these insurance companies you pay your money and after illness you find there are lots of things you are not covered for. I cant believe its classed as out patient when you dont have to attend. Also, they say im not covered for genetics and they say its a genetic diagnostic, so bashing my head against a brick wall. Will talk to surgeon to see if its worth paying for it myslef but its a lot of money at a time when money is at its worst.*sallie* says on February 18, 2011 at 2:28 pm

my story *Posted on:* November 17th, 2010 *by* CarenS

Hi everyone, I just want to share my story with you all. I was diagnosed with CUP in May this year following a hysterectomy in April. I initially had an ovarian cyst, but my cancer markers were found to be raised, hence the hysterectomy. Path lab results showed that I had cancer cells in my abdomen, but the surgeon said that everything looked normal. To date, I have not had any symptoms, and 2 CT scans, and a PET scan have shown no tumours.The oncologist told me, in May, that I was stage 4 as I had more than one site with cancer cells. He also told me, and my husband that I did not have years to live and that I would die from this. He was very blunt, and not very sympathetic, and you know the complete shock that follows such news. I asked for a second opinion, and this backed up the diagnosis. Once the shock had died down, I decided to do something as I needed to take control.The oncologist had said that chemo or radiotherapy would not do anything as they had nothing to aim it at. As a qualified nurse, I have managed to sift through huge amounts of info relating to cancer treatments. I have since found a wonderful book in the USA that has

helped me immensely. It is called: ‘Anticancer: a new way of life’ by David Servan-Schreiber. It details how we can fight cancer by modifying our diet and lifestyle, and explains how this works. Since modifying my diet in June, my cancer markers have reduced by almost 50%. There is also a website at http://www.anticancerbook.com The new updated version of the book is available in the UK from January 2011.I have also started intravenous mistletoe therapy, which works by stimulating the body’s immune system to fight the cancer. I have to go to a clinic in Kent once a week, and the doctors there are very hopeful as I am responding well. More info on mistletoe is available at:
http://www.anthromed.org/Article.aspx?artpk=313
I hope this info may be useful, and I’ll keep you posted. Good luck everyone and stay positive!

> Hi Caren,I have been reading your story and am sorry to hear of the problems you are having.As you will see in my story about my wife, she has secondary cancer in lymph nodes in her neck and is going through chemo treatment at the moment. No primary has yet been found.It is good to hear that you are using other methods to help you and I will certainly be trying to get the books you mention and visiting the websites. My wife is mentally stronger than me but at the moment not too strong physically due to her treatment. However, she likes doctors to be so direct with the truth that it scares me as when told of the malignancy in her neck I was shocked as I did not expect this but she just asked” what happens now”. Some doctors,as you will know, are very blunt because they are so far removed from patients or because they sometimes think that”s what patients want but they should establish how their patient feels before making a decision how to relay information. But there is no excuse for this without being sympathetic too. My wife”s professor was quite “matter of fact” when she first saw him, until she questioned his manner. Fortunately they now get on well. Thanks for the info you gave. ☺(Jim)*bewildered* says on December 1, 2010 at 9:35 am

> Jim do take a look at this it gave me courage to deal with everything and a positive outlook.http://www.thejourney.com/welcome.htm If your wife is up to reading do buy the book. Brandon cured her self of a tumour as bit as a football in 6 weeks. I found my lymph nodes responding before chemo after my first chemo my nodes had nearly gone after the second chemo they cant find the affected nodes and think when they now operate they may well not find any cancer cells in the nodes even though they new they were there. I believed whole heartedly that the chemo would work, its worth a try.*sallie* says on December 2, 2010 at 9:36 am

change of diet has helped me ***Posted on:*** **November 17th, 2010** ***by*** **CarenS**

Hi all, I just wanted everyone to know about a wonderful book that I found in the USA. It provides valuable info on how diet can target cancer cells. I am a qualified nurse, and have found it to be invaluable. I was diagnosed with CUP in May 2010, and have not had any treatment yet as they cannot find any tumours. However, my cancer markers have halved since starting this diet in June. The book is called ‘Anticancer: a new way of life’ and is written by David Servan-Schreiber MD, PhD. There is a website too at http://www.anticancerbook.com .The book is available at Amazon, aand hte new revised version is due for release in th UK in January. Hope this helps, Caren

My wife’s cancer journey *Posted on:* November 6th, 2010 *by* bewildered

Hi to everyone, Just recently become a member and thought I would tell my wife”s story as she has CUP. Her Journey with cancer started in 1999 where she was diagnosed with breast cancer and had to have a mastectomy. She was then diagnosed with lung cancer in 2004 and had to have part of the middle lobe in her right lung removed. Fortunately during all this time she was told she did not need chemo or radiotherapy. (I wonder about this now).This year she was told that the lump in her neck was a secondary cancer in a lymph node. I almost dropped to the floor in hearing this although she did not flinch too much as she said she expected this although I did not think it would have been malignant. I then remember her saying to me during her previous cancers ” you have to be strong as I can”t carry both of us”. This made me at least pretend to be strong.She has had all the tests that most of you have probably had e.g. CT scans, Petscan etc. But no primary was found and she was then advised to start chemotherapy. She is now on her 5th cycle with her 6th and possible last cycle to come. Like all of you I wonder about the future, as seeing her going through the chemotherapy is quite frightening although she has good and bad days. She has been rushed to hospital twice when her kydneys were packing up , her blood pressure was very low and she was dehydrating.She could not even talk to me to tell what she was feeling but was just passing out.I came across this website while looking for info on CUP and after reading some of the stories you have put on the site, I was a bit relieved to hear that many of you are doing well. I was surprised to learn that there is not much info about CUPalthough I believe that Cancer Research are researching or are about to research CUP. It was good to find this site and know that there are other people in similar situations who can support each other and share info. I never know when she is feeling unwell if it is to do with the chemo or her diabetes or just some other ailment. I am sometimes unsure what to do on her bad days. Can any of you tell me some of the usual side effects to expect.? She has had some problems with the skin on her hands and feet, is this a side effect?.Also has a sore throat sometimes and has recently had a chest infection. She also sometimes feels as if there is something blocking her throat/gullet. Better say bye now.Hope to hear any helpful comments any of you may have. Will keep you all up to date with how she gets on.with how she gets on.

> I am so sorry to hear about your wife and yes it is very difficult for you.
> Im currently undergoing treatment for cup breast cancer and im one of the very lucky subsets 1 in 5 have this good fortune. You can read my story on hear and my information so far with the chemo. Again im so fortunate at the moment i dont have many side effects. You can get mouth wash from your chemo ward for mouth sores and sore throats which you use 4 times a day. They are excellent. If you have any other problems that you are unsure about you can ask on your chemo ward I know ours are really helpful. You can get redness of the hands and feet which go away after chemo. People with diabetes tend to get more tingling in hands and feet as they are already compromised with the diabetes. This can go away after treatment. It is important to flush the chemicals through so drinking plenty of water and of course that helps with dehydration, if unable to drink much water sucking on ice cubes can help.I have researched cup never endingly and sometimes baffle the oncologists that i have seen. You have to be proactive in ensuring the best treatment possible as there are lots of oncologists but few specialist in cup. I find that they can tell you really stupid thing when they dont really understand or havent come across cup before.There is a set of guidelines on the front page of here set out as NICE. Trouble is it is only guidelines so a lot of hospitals dont take any notice. One main excellent hospital here Is the Royal Marsen in London.Im often flicking in and out of here so if i can help you with anything do let me know just reply on here or pm me. Good luck*sallie* says on November 6, 2010 at 1:08 pm
>
> Hi Sallie,Thanks for your response. Just to let you know I am a bit new to forums and sometimes not sure how to post,reply etc but I suppose ,like everything else practice makes perfect. So i will keep practising. My wife is not interested in computers, mobile phones etc. and she will say to me go and check this or that. She is then amazed at what info I have found. I told her about this site and she thought it was good to have such a place to be in touch with people who had similar problems and to share what is happening so that other people know what might happen to them or what they should ask etc.I forgot to mention before , that my wife has been told that the enlarged glands are reducing in size according to the last CT scan. She now does not mention the “lump” as often as she used to ,it is still there but smaller.So I hope everyone reading this will be a bit more assured if they have a similar problem. Sallie, I told her what you said about mouth wash and the tingling etc . She already has red hands and feet and quite bad sores on her heels and splitting heals She has been given some aquaes cream which helps her finger tips but not her feet. She will ask about the mouthwash.I have had to reduce my working hours to part time. I am self employed and obviously dont earn when I dont work. Can you tell me about any help in the form of someone helping look after my wife so that I could maybe get out more to work ,shopping. At the moment I have to juggle my work , looking after her,domestic stuff etc and find it quite exhausting. I have also borrowed a wheel chair for her on her bad days and wonder of you know of grants that may be available for someone in our situation

for anything that can help. Sorry to bombard you with all this but you may be able to give some advice.Also,I think it is good for carers/spouses etc to find out all they can about there loved ones illness so that they know what to do in an emergency like I had to do. I also check her blood pressure and temperature every day to monitor some of the side effects. I would advise other carers to do the same. The equipment needed is relatively inexpensive. It is good to be proactive as you suggest as you feel more in control and helps to divert your mind a bit. Better stop going on or i"ll be here all night. Thanks again for you reply and hope to speak to you soon. (Jim) P.S. I always explain to people who dont know what CUP is to make them aware. I was surprised when I said to my wife"s Dr the word CUP and he asked what that stood for. So I would suggest that any carer ,patient etc lets any one concerned know what CUP is.*bewildered* says on November 8, 2010 at 1:10 pm

Thank you John and Sallie for the info you have provided. I will check through this.
My wife goes to hospital next week for her 6th (and hopefully final) cycle of chemo. I will post her progress.Many thanks again.jim*bewildered* says on November 10, 2010 at 1:14 pm

Jim – I've put an article explaining possible side effects of chemo on the bottom of this page http://www.cupfoundjo.org/research_and_ … tions.html It sound rather alarmist and some patients, as you will see from this forum, suffer very, very few side effects. Certainly an oncologist I know feels that it is totally controllable. My experience is less positive but it just varies enormously from patient to patient.*john symons* says on November 19, 2010 at 1:16 pm

Thanks John for the info.Still trying to get time to check some of the other advice you sent. You always have so much to do and you tend to store all this in your head in some sort of priority order until something else comes along and that starts the priority order again. You end up getting your priorities all mixed up. Would like to take this opportunity to update members of wife's progress.The last ten days or so have been busy. Wife went to GP last week for check-up on blood pressure etc. I asked him why is she so pale looking? (as she has been for a while). He said she might be a bit anemic and decided to take blood. I phoned this week for results and was told that she was anemic and that a further test was required to establish iron levels etc (thought that was what first test was for).Anyway ,practise nurse took blood . Wednesday this week and wife goes in for 6th chemo cycle and staff were surprised that she came in in a wheelchair this time.Explained to them she was very weak and could not walk too far now.After they did blood test which showed hemeglobin level at 9 which they consider too low and informed my wife she would need a blood transfusion of two pints of blood after her chemo. Next day my wife got home and I phoned health centre to get their results (not telling them about transfusion) and was advised that the results were:first test was "normal" and second was "no action needed. I was astonished and asked to speak to someone medical to explain. Practice nurse explained that her hemeglobin level was 9.2 and was classed as better than last time when it was 8.2? .I then phoned hospital and they said that some medical staff think differently about what is an acceptable level but that on seeing her and her blood result, they thought it was necessary for the transfusion. I have heard that patients having chemo do sometimes have to have transfusions but was not happy that if she was not going for chemo this week then she would be going around with low levels of hemeglobin because of the results from the health centre. I thought other members should be aware of this so they can be on their guard. Dont believe everything you are told until you have checked with the right people. I must say that the staff nurse at the hospital was very helpful and explained everything. I am beginning to learn some of the medical stuff that I read about on this site. I think some members will end up as qualified as some doctorsbecause you have to find out about things to know how to get through all this. As other members have said "Keep Asking".Many thanks again*bewildered* says on November 20, 2010 at 1:16 pm

Your chemo ward should give you a booklet that you bring each time you go to clinic or chemo and in there are all the blood results so you can keep a check yourself.It should also give you the contact details and additional info to deal with your chemo or an emergency. They should also give you a card to carry in case of an emergency that tells anyone that you are being treated with chemo.You are

entitled to copies of your test results, you are also entitled to ask to see your records which i have done. You need to fill out a form and they arrange for you to access them and copies of what you want. If you want copies of your scans it will cost you. Once you have all that information you can send it to various hospitals for second opinions. I am assuming that you are in the UK. Some hospitals may ask for a written referral from your surgeon/oncologist but at least you dont have to attend the hospital for that second opinion.Even if you are not sure what you are doing sound as if you do and fight them every inch of the way. I have 3 friends that are currently being messed about by hospitals and none feel brave enough to write and complain.
Jim if i can be of any help at all please do ask. This is my email address for a quicker response. sallie@salliewaters.co.uk.*sallie* says on November 22, 2010 at 1:18 pm

Hi Sallie,Thanks for advice.I was not aware that the hospital should complete a book for you to keep and check yourself.Only knew this when you told me. Fortunately this should be my wife"s last chemo cycle. She gets a CT scan in 2 weeks and will then see the oncologist to find out how well it has worked and what happens from then. Don"t know if they will want to remove the lump in her neck as although it is still there ,it has shrunk. I also don"t know if they will continue to search for the primary. Should they do this after a certain time has elapsed or just don"t bother now till something else happens ❓In the meantime she has to go and see her GP to check her blood (again) and I will be looking for an explaination about her last results.speak to you soonJim*bewildered* says on November 25, 2010 at 1:19 pm

Hi Jim – I guess much will depend on the efficacy of the chemo treatment in terms of "chasing the primary". Investigations are unpleasant and distressing if they lead nowhere; only worthwile if they add to the "picture". If the treatment is proving effective that in itself may give more clues about the primary. Finding the primary is important in relation to understanding the original genetic signature of the tumour(s) – when it has spread it may develop also some different genetic charactersitics which is why it makes it so difficult.*john symons* says on November 25, 2010 at 1:19 pm

Hi I agree with John, however they do continue to look for the primary for the rest of your life sometimes its microscopic and in time it may or may not show itself so they continue to look for it through routine check ups. As John says though they dont continue to put you through endless test to no end. I hope all continues along a good road for your wife. Are you keeping well and as positive as you can be through all of this. Is anyone taking care of you? 🙂*sallie* says on November 26, 2010 at 1:20 pm

Hi Sallie and JohnAgain thanks for the info. Can"t believe Sallie that they have your diagnisis wrong. What a mistake to make.As you say, wish they would get their act together.We don"t expect doctors to be gods but do expect them to know, for sure, before saying anything definitive.I spoke to my wife"s GP this week and questioned him about the carry on with blood results the week before. He explained that he thought that a hemoglobin level of 9.2. was o.k but would prefer it to have been higher. What! he has just contradicted himself. Anyway, he now has some knowledge of what to look for in a chemotherapy patient. (not 9.2).This week my wife"s hemoglobin level was 12.5, much better I believe. Her blood pressure seems to be now going downwards from a high when she had the blood transfusions. Her pulse rate also remains too high at 100-125. I assume this is more related to the chemo than anything else. My wife is very weak at the moment and Is now using a wheelchair if she has to go out anywhere as she cannot walk very far.She is feeling a bit down to say the least and does not feel very confident about the outcome. She is still saying that as soon as she is able to , she will go over to Tunisia and have them look for the primary. If anyone can find it we are confident they will. Thanks Sallie for your concern for me too. Yes it is hard, apart from doing all the domestic duties it is harder not knowing what to do when she does not feel well. Is this to be expected? should I call out a doctor?. ..Wish I had known about this site earleir then I would know more about cup,chemo and cancer in general.Unfortunately our son is either burying his head in the sand and does not want to think about it ,or, he has"nt got a clue how serious the situation is. His wife is not helpful with her matter of fact comments and the way she “controls” his life. Sorry to go on about this ,but it makes me angry that they dont seem to understand that my wife needs all the support she can get.I am sure many other people are in this situation too. Speak to you soon.Jim*bewildered* says on November 27, 2010 at 1:21 pm

Hi Jim,Firstly here is a site that may help you to understand the bloods a little better.http://www.labtestsonline.org/understanding/analytes/cbc/test.html
I am so sorry your wife is so weak and you dont appear to have much support. Do you have a FORCE or Cancer Macmillan, these can be great offering free massage, reiki, reflexology to both you and your wife. They can also offer counselling, have an experienced oncologist to help you understand what is going on with treatment, bloods etc. They also can provide support to come and visit your wife in her home. Such an excellent service we have FORCE in Exeter and its such a good place to go and sit, chat have tea etc. We are lucky because its in the hospital grounds so i can go there between appts. These organisations may be able to help your son understand what is going on if he is willing.You should be getting benefits to help with your wife’s care so its worth contacting Social Security and finding out if your claiming all that you can. Also, Social Services who may depending on how severe your wife’s condition is may be able to provide care and rest bite for you. There is so much out there its knowing where to look. Have a look at the force and mcmillan web site as there are free phone numbers that you can ring to talk people about all things.Where abouts in the country are you Jim?*sallie* says on November 27, 2010 at 1:22 pm

I don’t know about FORCE but think Macmillan could be very helpful. Also, is there a Maggie’s Centre near you – sounds a bit like Sallie’s description of FORCE? See this page for more info http://www.cupfoundjo.org/research_and_ … index.html *john symons* says on November 27, 2010 at 1:23 pm

A few helpful pointers on state help. If your wife is in a wheel chair – ask your GP to help you with applying for high rate disability allowance- we now have a blue badge which has brought hjelp in ways I could not have predictyed. Whilst Max is on Oromorph- for cough he should not drive- has not stopped him trying to paint the celing when I was at work last week thouigh… I digress- I can now park near shops and postoffice whilst he does the jobs he wants to do whisch is very helpful- also free entry to congestion charge zone on way to Marsden weekly.He also is getting high rate attendance allowance which helps with any costs due top reduced working hours for you aas carer- and there is carers allowance.The macmillan website points to many benefits which you may not be aware of. Our friends have been great and have organised a rota to help ensure someone comes in each day whilst I am at work to break up the day at home.Little changes to many working patterns have made for an incredible supportive network from firends and familyGillian*gillianb* says on November 28, 2010 at 1:24 pm

Hi Sallie,Thanks again for the info.I live in Glasgow and my wife attends the Beatson Cancer Centre.They have a group called “Friends of the Beatson” in the hospital but they tend to operate a postcode lottery there according to other patients and do not ,strangely, allow a patient”s carer/friend in with the patient. My wife is not that interested in reiki, head massage etc but would probably have dropped in if I could have been with her and they did not operate in the way they do. There is another group called “The Maggie Centre” and I probably would have went there to see how they operate but my wife is a bit unsure about going and in any event does not feel well enough at the moment to go. Through the advice both you and John have given ,I have contacted McMillan and they are intending to visit us at home to discuss any financial help available. I also have the name of a McMillan nurse who I can phone for info .I will wait for the outcome of my wife”s CT scan next week to see how things are doing with the chemo before I seek any further advice at the hospital. But through being able to visit this site I feel more able to ask questions that I might not have otherwise asked.I will keep you all posted on progress. Thanks again. Jim 🙂*bewildered* says on December 1, 2010 at 1:25 pm

When your wife up to it, I would urge you to try Maggie’s Centre. I’ve heard nothing but good reports.*john symons* says on December 2, 2010 at 1:26 pm

Hi John,Thanks for recommendation for Maggie Centre, will try to go when wife is feeling better.She has just finished last cycle of chemo this week and has had CT scan of chest, neck, abdomen and pelvis. She sees lung consultant next week and he may well look up scan on computer (as he would normally do) or we may have to wait to see Professor Evans at appointment on 4th January. She is feeling better this week .I think finishing chemo is helping her phsycologically as she is trying to do more physically but is still very weak.I am still concerned about her face colour as she is still very pale although not as pale as before she had blood transfusion. Is this quite normal or should something be done ❓I had a look at the articles on diagnosis and tests you posted on sallie”s story and I wondered how any medical person would react to being asked all the questions listed. I suppose you would have to condense them a bit to suit particular circumstances although I think some would not be able to/want to answer them. I was a bit concerned about the prognosis for CUP patients , it is a bit worrying. Anyway, thanks again for your advice. (can you or another member answer me about skin colour I mentioned above. 🙂(jim)*bewildered* says on December 10, 2010 at 1:28 pm

Hi to you all,Thought I would post an update on my wife”s situation.
Been advised by respiratory consultant a problem with one of her lungs from a previous CT scan had now cleared up and scan now showed no sign of anything abnormal. May be that antibiotics she had have cleared up any infection.He was also kind and interested enough to check her recent scan and advised that the enlarged lymph nodes in her neck/chest had responded to chemotherapy and were now reduced in size. Furthermore, her oncologist phoned her to advise that he was happy with the results of the scan but did not go further in to it and will see her in January. Dont know where she goes from here. ❓Still feeling very tired and weak. Had her blood taken today and will await result to see if there is anything there that is causing her weakness. We wish you all a better 2011.P.S. John, thanks for brochures received today. Will start to circulate these in the new year. 🙂*bewildered* says on December 29, 2010 at 1:30 pm

Hi Everyone,Just like to keep you updated on wife’s progress.She went to appointment on Tuesday this week to see Prof. about outcome of chemo and CT scan. Did not get to see him but his registrar took his place as he was working on his own and running late. (normal) Wife, sorry , her name is Betty, was a bit dubious about seeing someone else but thought she would go along with it so far and see how it pans out. Turned out that the registrar was very good in that she was a goodl istener as well as a talker. She advised that the chemo had worked well in that no further cancer spread had occurred and CT scan showed reduction in size of lymph nodes. She stated that she, or the Prof, would see Betty in 2 months and decide what happens next. She did add that more chemo or even radiotharapy may be considered. She also explained that the 2 months would give Betty some time to recover. In the meantime she thought that Betty looked and sounded a bit aneamic and would have a blood test carried out. Have since heard that hemoglobin level was 12 which i believe is o.k and shows no aneamiaSo, I think this is quite positive although will have to wait. Betty is still focusing on going over to Tunisia if she is strong enough,hopefully before any more treatment starts. Speak to you all soon. Jim 🙂*bewildered* says on January 6, 2011 at 1:32 pm

Thanks Sallie ,John.Looking for help with obtaining info of an insurance company who would supply travel insurance for cancer patients without too much fuss and high costs . Found a list on macmillan website.(quite a lot). Hoping someone could actually recommend company who was reasonable and understanding. Anyone know of such Regarding cancer info literature; Have spoken to practice manager at health centre and gave her some of the foundations brochures.She was very happy to receive them and in fact read one right away and thought it would be good to have these to give to someone who needed some contact with other CUPcakes. She did explain that there are so many leaflets available in doctors surgeries, which she agreed were usually a load of useless info.

e.g. how to deal with a cold??? etc. I am sure she will come accross someone who will be happy with some info on CUP. Also told her about info brochure from Macmillan which had been produced in conjunction with this foundation. She will also get some of them.Doctor himself informed me his practice usually has only 1 or 2 CUP patients per year.thanks again (jim)*bewildered* says on January 14, 2011 at 1:35 pm

Hi Everyone,Yes I am up at 5.00 a.m. Wife was sick last night and have had to stay up to make sure she is o.k. She was told recently she may have fluid in the lungs as she was very breathless.GP gave her antibiotics and water pills. This seems to have helped her breathlessness a lot although she still has a cough and is being sick from time to time, she also feels dizzy, and generally ill.. She also has eating problems in that she does not seem to have any appetite and will tell me something she fancies .But when I make it for her she either does not eat it or eats very little. I was wondering about cough,breathlessness etc and asked nurse specialist at cancer centre if these were a side effect of chemo and was advised no! Since discovered that ,yes, chemo can affect your heart muscles and allow a build up of fluid in your lungs.This is now 2 months since chemo stopped and she does not seem any better as far as side effects, in fact I think they are a bit worse. Anyone have info on how long side effects last for ❓.Ongoing dialogue with nurse specialist about awareness of CUP and after she checked with Macmillan about their booklet called “understanding CUP” (I would advise anyone with CUP to send for a copy,free from Macmillan) she advised me that this Foundation was not mentioned in it and that it must be out of date. I then received a copy (several actually) that I had sent for and phoned her up and left message telling her to look at page 2 and not the back of the booklet she was looking at. Funny she has not responded. ❓.The difficulty in getting basic info is appalling. So I expect to see either the Foundation brochure or Macmillan/Foundation booklet next time we go to Cancer Centre.I will keep you all posted. Any one have info as I mentioned earlier about recommended insurance company who will provide cover for cancer patients without ripping us off. I have checked with some who either will not cover or are looking for a fortune. speak to you all soon.thanks (jim)*bewildered* says on January 30, 2011 at 1:37 pm

Finding something OK to eat is really difficult. I know the Penny Brohn Cancer Care (the new name for Bristol Cancer Help Centre) have done some work on diet. You can get their link from this page http://www.cupfoundjo.org/research_and_ … index.html Thank you for pushing the medical world into recognition – I’m afraid it is a battle. Lack of cancer/ chemo knowledge is awful.
Hope things improve for your wife. Are you getting the consultant’s view as well as the nurse’s on the present symptoms?*john symons* says on January 30, 2011 at 1:38 pm

Hi everybody,Thanks for info John,will have a look re diet. Wife doesn”t see consultant till March and we will be asking about side effects and about recent events re; breathing problems. GP seems more responsive when visiting him as after 1st antibiotics, breathing seemed a lot better but the problem returned and went back to GP and he gave further Anti B. But he also decided to contact respiratory consultant and arranged appointment which my wife has now attended and she too appears to be behaving responsively.She arranged x-ray there and then and also took blood to back up anything x-ray showed or did not show.She waited for x-ray result and saw Betty again. I did remind her that when Betty had tumour in lung this did not show on x-ray and I was not confident with just an x-ray . She advised that she will be checking blood readings to confirm things and will be in touch within days. This is the way it should be , don”t have patients waiting for weeks for results. Well done this time.!Thanks Sallie for your kind thoughts.Again , can I ask if anyone knows travel insurance company that will cover Betty”s situation at a reasonable cost ,anyone got experience of this? Government has now lifted ban on travel to Tunisia and we are hoping that ” god willing” we can go next month and need to try to get insurance cover.Speak to you all again soon. (jim and betty) ☺*bewildered* says on February 12, 2011 at 1:40 pm

Good- better news.Don’t personally know about travel insurance other than it is a nightmare for those with any illness or over a certain age. Try asking SAGA? They might not be right but it cold give you a feel for the prolems and they might suggest someone else?*john symons* says on February 14, 2011 at 1:40 pm

Hiat least things are moving in the right direction again for you both. Re. travel insurance, this is a breast cancer forum that i use regular but there are loads of topics on here about cancer and insurance might well be worth your while having a trawl through and a read. http://www.breastcancercare.org.uk/sear … insurance/ Hope you get to travel to Tunisia soon.*sallie* says on February 16, 2011 at 1:41 pm

hope you find something, i only found out the other day once you have had cancer you are classed as disabled, i thought well thanks for asking me….. things like that make such a difference on insurance!! *sallie* says on February 17, 2011 at 1:43 pm

Hi everyone,Sorry I have not posted for some time now partly due to computer problems but mainly due to everything that is going on with my wife"s cancer. So much has happened and I will try and post the main points.Having been told in March by my wife"s oncologist that her cancer had spread and she would have "months rather than years" left to go, we were devastated. He gave this diagnosis without checking a recent scan ,as he could not find it.???She was very ill at this time with severe weakness and breathing difficulties. Despite his advice not to travel, we went to Tunisia as planned. She had a tough time there but got checked by a lung specialist and cardioligist who confirmed she had left heart failure caused by the chemo she had. This was despite me questioning this issue prior to going away. So she had this new diagnosis-the heart problem was now more serious than the cancer. Back home and at the clinic I wanted to pull the oncologist over the table but my wife had warned me not to say anything and she did not tell him about her new diagnosis. After seeing her GP, she was referred to a cardiologist here who confirmed the diagnosis from Tunisia.The oncologist then phoned us at home to say that her lungs were clear "was this an attempt at an apology"I do not mean to be alarmist ,but fear that patients are not being told that some treatment can cause heart failure. I believe that not enough info about serious side effects is given to patients and /or carers. I think a leaflet should be given to patients, just like you get with a prescription, so that patients are aware of all possible side effects, not just the more minor ones, and more importantly , know what to do when things are happening. So in effect, the difficulties she was experiencing was not caused by "normal" side effects of the chemo but by the now damaged heart. As is probably told to all cancer patients, yes you will feel tired and weak during and after the chemo ,but with no one realising that it was her heart causing these symptoms.She has now had radiotherapy to her neck lymph gland as the chemo shrunk it initially but it is now much more swollen than ever.We dont know where we go from here now . She is now on several medicines to control her heart and sees her oncologist in July. I will also have to chase up a scan she should have had by now prior to going back.I am hoping to remain strong enough to start a campaign to force all "cancer treating doctors" to provide the info required about all side effects of treatment. Many thanks for listening. Jim*bewildered* says on June 28, 2011 at 2:06 am

Hi Jim – thanks for your post. I'm very sorry that you are both having a very tough time and you do not have better news. Glad you made it to Tunisia. I know that some clinicians are hopeless about explaining side effects. They just don't get it. The patient and carer live with them 24/7 and some oncologists believe that it simply isn't a big problem, or that it is not their field. Cancer nurse specialists, if you get access to one, are much better on this score. I think you are right to highlight what doctors should do but often don't. Better patient information is vital.BWJohn*John (Moderator)* says on June 28, 2011 at 7:59 am

Hi Jim, Sorry to hear your news but good as John says you made it to Tunisia.My own experience is that i have been in control of my own treatment and double and triple checked everything. At our hospital i have been told everything, i have copy of all my hospital notes and know exactly what is going on sometimes faster than the oncs and surgeons know. I cant advocate enough to be the master

> of your own destiny even when at times you feel like giving up through sheer exhaustion.
> I am monitored by echo scan every 3 months for Herceptin and when on chemo as well was monitored by echo and Ecg every three months. Chemo could not go ahead if bloods, echo and ecg were not in place.It must be one of those postcode lotteries as to how good your hospital is. Jim keep battling and as always if I can be of any help please ask.My best wishes to you both. Sallie*sallie* says on June 28, 2011 at 9:47 am

squamous cell cancer in inguinal lymph node *Posted on:* October 25th, 2010 *by* Karen

My jouney began on July 30, 2010. Having had kidney cancer 4 years ago, which was completely cured by the removal of the affected kidney, I have had annual CT scans as follow up to be sure there was no recurrance. This year an enlarged lymph node was discovered in the inguinal area.The node was removed and found to contain squamous cell cancer which was totally unrelated to the kidney cancer.For a month I underwent every test and exam imaginable including xrays, PET, colonoscopy, upper GI endoscopy, mammogram, ultrasound of ovaries, bone scan, multiple gyn and anal exams and bloodwork.No other signs of cancer were found. Diagnosis: CUP. I was referred to an oncologist whe recommended several cycles of cisplatin, docetaxtel and 5-flourouracil followed by 5-6 weeks of radiation 5 days a week to the inguinal area.After doing some reading and following some links from this website, I decided to seek a second opinion from MD Anderson in Houston, TX. While that was a nightmarishly long process (6 weeks of "we just need one more piece of information") I finally got the call last week that I have an appointment ! I will travel to Houston in two days to see Dr. Varadhachary.My hope is, of course, that they will be able to identify a primary site. If that is not possible, I would like to get their recommendations for the best treatment and then return home to Oklahoma to have the treatment locally.The long wait for the appointment at MD Anderson has been incredibly frustrating because it has now been 3 months with no treatment, but my oncologist here keeps assuring me that is was safe to wait since there was no evidence of disease present in my body after the lymph node was removed.we will see…Karen

> Well done Karen for persevering. I've met Dr. Varadhachary (she spoke at our conference last October) and she is contributing to a paper we are producing at the moment. I believe that you have booked to see the best possible person at this impressive hospital. Best of luck.*john symons* says on October 25, 2010 at 9:39 am

> I am now home after my visit to MD Anderson. They had nothing to add as far as identifying a primary tumor site. Dr. V. did recommend a slightly different chemo regime than what my doctor here had in mind. A new CT scan revealed no new metastasis which was great news. Dr. V. said that in her 5 years of treating CUP patients at MD Anderson, she had only seen 5 cases that presented just like mine. Those people are all still alive, another great piece of information. Hope to get started with my treatment within a week or so. 😀Karen*Karen* says on October 30, 2010 at 9:40 am

> Hi Karen – My diagnosis was SCC of unknown primary – also in the inguinal gland. I had surgery and 5 weeks radiotherapy and have remained cancer free since. I hope you will be encouraged by the fact that in July I will be a 12year survivor, and my primary remains a mystery. Hope to hear from you soon and to know how you are.Take careLyn*aussieangel* says on April 17, 2011 at 5:21 am

> Thank you for the encouraging note. I have finished with the prescribed treatment of chemo and 33 radiations. I feel fine except for my energy is not yet back up to normal and I still don't have much hair. Plan to return to work in another week. Will have a follow up CT scan in June and periodically after that to monitor for recurrances. I am feeling very optimistice that the cancer is gone and that I won't have any more problems with it.*Karen* says on April 21, 2011 at 1:50 pm

Squamouscarcinomainarmpit *Posted on:* October 16th, 2010 *by* christine

Hi everyone. I am Christine. Found lump in armpit beginning of May. Had mammogram, ultrasound and core biopsy, then ct. scan then told was malignant but also had primary tumour somewhere. Had 16 weeks of scans mri, g.i. endoscopy, throat and nose endoscopy, cervix and womb investigations, minop operation on nasal cavity and finally PET scan. As the oncologist says every test known to man, but no luck in finding primary. Am under two hospitals but neither have heard of a squamous in lymph node in armpit. The have definately ruled out brest cancer as I have to wrong cells for that so as squamous is most common in the lungs am having chemo for 12 weeks based on lung cancer.Am told this should also help the secondary. Having G and C. chemo whick is mainly for squamous cells. After this is done will be having radiotherapy on armpit. Theuy hope to avoid surgery is possible. I still do not think it is my lungs as the only problems I ever have is with my throat and constant catarrh. My oncologist has never dealt with an unknown primary in fact the two hospitals only get two patients a year on average that get unknown primaries so there is no-one who specialises in this problem. I just wonder is anyone has any experience of this. I am half way through chemo now and doing ok, except for what goes on in my head, which you all know exactly what I mean.

> Our hospital here In Exeter Devon only deals with about two unknown primary a year. You have to be pro active and research as much as you can yourself. My oncology team say i have kept them on there toes and made them think outside the box. I have also educated them as much as they have me. Researching can bring up scary things as well as positive but go for it. Best wishes and keep us posted. Hope all continues to go well. 🙂 *sallie* says on October 16, 2010 at 9:43 am

Incurable *Posted on:* October 13th, 2010 *by* kilterbagpipe

My wife Linda and I are very keen Moto GP fans and in June this year went to Italy to watch the race had a fabulous time came home fit and happy, however a few days later I was driving along and for no reason touched my neck above my right collarbone and felt a small lump size of a pea didn't think much of it , a day or so later told my wife, out came the obvious answer you better go and see the doctor which I did and he made an appointment for the local hospital saw a specialist who took a biopsy , I had a CT scan, I had X rays and an ultrasound examination plus much proding and poking I was called back to see the specialist on the 10th of August to be told by the oncologist I had cancer of unknown primary and the lump in my neck(by now the size of a tennis ball) was a secondary tumour and that the scan had found two more in my chest cavity Linda was with me at this meeting and I asked the obvious questions I was told that it is incurable and inoperable and if I was not fit and well as I was he would give me three months however he would try and give me two years of quality life ??? a course of chemotherapy was organised and my first session took place on 28th August the first week after was OK but the the chemo kicked in and I spent the next week curled up in a ball on my couch feeling that I would die, after that period it eased a little and I was back for my second session on th 14th September again not too bad at first but after the first 10 days every thing went from bad to worse all the chemo symptoms I had as per the book I seemed to have but worse I was taken into hospital on 29th Sept with a temp of 104F I was kept in a week and the chemo stopped I had a scan yesterday and see the oncologist tomorrow I must say at this stage the lump in my neck has really shrunk Both Linda and I are now coming to terms with the facts and are both thinking positive I will let you know my scan results Regards Gordon

> I am so sorry to hear your story, do remember most of us with cup are incurable because they cant find the primary but that doesnt mean we cant live a reasonable length with quality of life. Im hoping after my treatment that i will be in remission for some years. They have told me they expect it to return within 5 years but they will be watching and waiting to treat it. Keep your spirits up and keep positive because it certainly seems to work.

wife of new cupcake! *Posted on:* October 11th, 2010 *by* gillianb

Dear all Max wishes me to share his story since we find reading all of yours so helpful.Max previously fit and well- (much more so than I!) became unwell mid July 2010. He had pain in the abdomen and shoulder tip pain. GP arranged scans x rays and blood tests- all cut short when the lab rang within an hour of the blood test to go straight to the hospital because his calcium level was dangerously high. Having a tumour that switches on calcium imbalance made for rapid diagnosis of cancer and a fast tracking! Max has widespread metastatic disease in his liver – predominantly in the right lobe and some fine micro nodules in the bases of his lungs. All scans have been negative for finding primary including high resolution CT, MRI , PET scan endoscopy , colonoscopy etc.His immunohistochemistry of liver biopsy points firmly to Gastrointestinal or pancreatobiliary source ck7 and 20 positive. As a result his oncologist started him on EOX regime to be 8 cycles-unfortunately Max has had problem with some of the toxicity and has only been able to tolerate 3 cycles. The latest scan has not shown any real improvement in the liver mets – the hope was that they would shrink sufficiently for a liver resection, this is now unliekly since the lung mets are proving to be more active than previously. We are now awaiting the results of molecular profiling sent off last week in order to tailor chemotherapy better to the probable primary site.This website has provided so much invaluable information for which weare really grateful.I am happy to chat on and off line with anyone on carer/spouse feelings/needs.Gillian

> Hi Like you this site is invaluable to me and its good to hear from cups and carers. My partner doesnt use the computer so im afraid we wont get his story. What i find so hard is that im so incredibly fit and well and they are about to make me poorly. My only site is my lymph nodes with primary assumed to be the breast. This puts me in the good sub set so im really hopefull. They have said they are going to blast me in the hope to completely kill or shrink the cancer and then an operation to remove all the lymphs followed by more chemo. Life changing me thinks but im alive and thats what matters. 😀 Hope Max keeps well for as long as possible as research is bringing about so much change there has never been more hope for CUP patients. *sallie* says on October 12, 2010 at 6:03 pm
>
> Max doing much worse I am afraid in the short 2 weeks since sending off tissue dramatic spread in lungs and liver worse too. Only symptoms are difficulty breathing when talking although remarkably good exercise tolerance(we went on tube to matinee to see WarHorse last Thursday!) I had misunderstood what they were doing with mol profiling- I thought they were looking to better define the tumour origin- they are looking gene mutation- if there is mutation he will do worse with biological target agents and I am told 80% CUP patients with GI have mutated- I had not read about this previously. Starting a milder regime later today in case it was pancreatic…
> Gillian *gillianb* says on October 21, 2010 at 6:05 pm
>
> So sorry to hear the latest news, lets hope things do improve, I have a friend who has prostate cancer of course not cup but the cancer was spreading all over his body. This started 5 years ago and today he has announced he is in remission and that the bowels and stomach are clear. There is always great hope. I am hoping beyond hope for you. *sallie* says on October 21, 2010 at 6:06 pm
>
> Time to post an encouraging update! Max is now on 2 nd cycle Gemcytabine and yesterday had the 2nd cemuxitab – monoclonal antibody infusion which the molecular profiling revealed might be effective. The disease appears to have stabilised and clinically he is not needing as much oxygen support as before. best wishes Gillian *gillianb* says on November 28, 2010 at 6:07 pm
>
> Further update: Max was doing really well on Gemcitabine and cemuxitab – unfortunately 2 weeks ago developed a pneumonitis. He has responded really well to elephant doses of steroids and came home yesterday. We have a couple of weeks off now whilst his body recovers and look at what next! I wish you all a fantastic festive season with your families enjoying the mopment. None of us know

what is round the corner. A Happy and Healthy New YearGillian *gillianb* says on December 24, 2010 at 6:09 pm

I thought I would post an update to you all. Max is completing 2nd cycle of a third different chemo regime having being given the option to stop chemo since the disease progression was so fast- he nevertheless wishes to persevere. The latest regime paclitaxol seems to be buying time.He is having major side effects in terms of steroid induced muscular atrophy- he can't move very well and we have every appliance known to man to help us. I installed a stair lift last week- you can rent them even for curved stairs.|He also has diabetes from steroids.On oxygen 24/7 we have a concentrator upstairs and downstairs and transporter small bottles. I have help in the form of carers to help every day in the mornings courtesy of our wonderful health service.Now you might think this all sounds gloomy- but Max had a birthday this week and we celebrated in style. He is into horology and watches – so we invited an expert to a talk at the house at the weekend. And yesterday succesfully ventured to a great restaurant in the City of London.See our photos here:http://www.facebook.com/album.php?aid=2 … cbe0a41c58

http://www.facebook.com/album.php?aid=2 … 08b68a0b67
Chemo Friday (today) and scans for update on how we are doing next Monday…
We have had to recalibrate what is a treat- outing to restaurant- but not going to niece wedding abroad- too hard sadly.Hope you find this update helpfulGillian*gillianb* says on February 18, 2011 at 6:11 pm

Dear allI am sorry to let you know that Max passed away last Friday managing to last until after his neice's wedding on the Wednesday so as not to spoil the celebrations. Our sons were able to fly back afterwards in time .Max was at home throughout the last phases of his illness and lived life to the full.I thought you might like to read the text of what I said at the mourning service.
Golden MomentsTonight is the Yahrzeit (anniversary) of my father in law Joseph Braunold zichrono livrocho (of blessed memory) who was like Max taken too early from his family aged 60.I have therefore been reflecting on the loss of Max and my father in law and how different the experiences are.People always think of Cancer as a terrible wasting disease and that death when it comes will inevitably mean loss of dignity and great suffering. Are there positive strengths that we can take from Max getting ill with cancer last year? As a doctor we are always taught that a terminal illness gives the patient the opportunity to put their affairs in order. I always thought I understood what that meant. Monetary affairs and asking for forgiveness perhaps. But the last 6 months or so have taught me what putting affairs in order really means.We as a family were given the opportunity to learn together but led and inspired by Max's example to live in the Now and to appreciate the present time and what we have.Max was quite extraordinary in his ability to see the positive out of situations. As his world shrank and he was less able to move around and became confined to his room- he enjoyed actively watching a football game with his friends shouting so loudly that the rest of the Rise could hear as he cheered Spurs on – to a goalless draw!2 weeks ago he went into urinary retention and needed to have a catheter fitted, typically of Max he said wow this is amazing I am a new man- why didn't I have one of these years ago I don't need to go to the loo anymore. His sense of humour was extraordinary , having his pressure sores dressed that were excruciatingly painful- he groaned impressively whilst holding onto me. He remarked between groans that the nurses could sell his groans to a sex shop. The nurses asked him if he had ever been to a sex shop and he said I can't tell you in front of my wife! Max was able to concentrate on his relationships with his friends and we both felt incredibly fortunate to be given that opportunity . Many men I have observed feel that the friends that they have have are family friends or their wife's friends but not their own special friends . During Max's illness his friends solidly supported him and he basked in the support they gave him. He put extra vigour and energy into the time they spent together and held synagogue committee meetings in his bedroom accompanied by pancakes ice cream and whisky! Since Max's diagnosis 8 months ago till last week he was not able to go to the synagogue anymore but we held open house every shabat for Kiddush and he enjoyed the informal social gathering which reinvigorated him

every bit as much as spinach did for Popeye!I assumed a very practical role in trying to provide something to look forward to in every week. As many may know Max was meticulous in noting everything in his diary, what was happening next. I found it irritating to have to give him details of a meeting that I was attending at bma house, the venue of which should have been immaterial to him. However he wrote it all down. And I came to understand that the diary represented a measure of control in a world where he had so little and he could do so little for himself –Pleasure in the moment we learnt to enable though a series of golden moments planned around Max's abilities. In good health a treat was a holiday in Costa Rica. We moved to enjoying simpler pleasures, and as a family sought out new experiences that we could enjoy together .Finding cinemas with a sofa- in Hampstead where they bring you a cup of tea. Going to see War Horse in the west end for a matinee. Later going out became impossible. Bringing a child every few weeks over to see him, Tami Nathan Rafi and Libby jointly and severally alternating and then Daniel and Michael also joining in. Max and I felt very supported with something to look forward to. Buying a new laptop that enabled skype into his circle of vision; bringing dvd and cable tv into the bedroom watching movies together and finally converting old lps into mp3 format so that we could enjoy the sounds of the 70s together on the ipod .Max's birthday was a unique affair – we had not known if we would be able to celebrate it but the time came and we decided to hold the equivalent of a whiskey tasting at home for a small number of friends. Max was always interested in watches and we invited Jonny Wachsman to talk and run the evening. None of those present know just how ill Max was in the day time but he lay down fully clothed for an hour before hand just to get over the exertion of getting dressed and then proceeded downstairs to vigourously enjoy the evening. Libby's birthday party held in his room 3 weeks ago had Max cheating at pass the parcel and dancing in his bed to the Hokey Cokey.We managed to enable a bath – rather like a paddling pool on the bed only one week before he died and Purim Colin reading the megillah in his room.I think the outstanding golden moment for me is the evening when 5 of the men sat with Max watching a copy of the kings speech – and the laughter shaking the house.I wanted to finish with a word about pain and courage. I had always thought Max was a hypochondriac – he was not good with pain- he would call for antibiotics as soon as he sneezed. But this last few months unbelievably swollen and uncomfortable he didn't complain once and grinned and joked through the discomfort.So to come back round to the loss of my dear father in law Jo who was so sorely missed and grieved over by his sons and widow. They did not have the opportunity to say goodbye and to demonstrate their love and appreciation as we were fortunate enough to be able to do with Max.His strength of character helped us to face his death with fortitude and will carry us all forward solidly into our new chapters of golden moments. March 30th 2011*gillianb* says on April 2, 2011 at 11:07 pm

Dear Gillian – so sorry to hear your news. I found the address very uplifting. Thank you for including it. It will be a very difficult time for you and your sons, I realise, but I'm sure you'll take comfort from what you were able to do in the last weeks and the love that you shared. Best wishes, John*john symons* says on April 3, 2011 at 10:32 am

Another cupcake! *Posted on:* **October 10th, 2010** *by* **marklingao**

Hi All I started having back trouble in Jan this year, my GP told me to take painkillers and rest. for the next 5 months I had a series of x-rays and blood tests but nothing was found. Wasn't to impressed with my GP's approach to my complaint and by may work was on my back because of the amount of sickness I was having. Then one moring at the end of may I couldn't get up of the sofa, there was this painful spasim in my right leg everytime I tried to put pressure on it. Long story cut short I spent about twenty hours on the sofa eventually calling an emergency doctore out. He recognised straight away that I had a serious problem and admitted to West Middlesex hospital were I had an MRI scan the same day. 5 days later I was told that lessions were growing on my spin, within two weeks I was having radiation treatment at charing cross. The doctor there told me that without the radion treatment I would soon lose the ability to walk. The radition worked a treat I can still walk and feel stronger than I did in may. After being told about the lessions on my spin I was then told a few days later after a biopsy that it was definately cancer but that my primary cancer was unknown. A few weeks later they confirmed that I also had secondary cancer in my liver, spleen and lower lymth nodes. I was then refered to Hammersmith hospital were I have agreed to join the cup1 trial under the supervision of Dr Hasam. I have never met him but did google him and he as a very impressive record. Also he his head of the cup1 trail in the UK and I must say that since hammersmith is where he is based the treatment I am getting is well above the NICE guidelines. I am 5 cycles into my treatment and last week recieved the good news that a recent scan shown a 40 percent reduction in my tumours. I am currently undergoing an 8 cycle ECX chemo treatment. I am getting a lot of support from family and friends but they all talk about fighting the fight and getting cured, it gets tiring tell them I ain't going to get cured and that I am looking for prolonging my life for as long as possible. I have an 11 year old daughter and my main aim is to see her grow up for as long as I can. But with our type of cancer no one can commit to estimates and I believe the there are very few statistical records concerning cup to go by. I suppose one consulation is that I know I have a terminal illness and I have a chance to spend quality time with friends and family. Back in may I could have just dropped dead with an heart attack or got hit by a bus, then I wouldn't have this special time left with my daughter. Any way I hope this story is useful to some of you and feel free to ask any questions especially about the trial. Mark

> Hi Sallie I'm on my 5th cycle and this is the best one yet, must be getting use to it. I didn't handle the first two cycles to well, would stay in bed for a few days after. Mainly tired weak but thankfully not sick, although you always get that nausia feeling. I also hate the chemo day when attached to the drip, its just the sick feeling it gives me. Its difficult to accept that they are pumping you with poison but on the other hand its saving or prolonging your life.I never kept a diary but would advise you do and record every feeling because believe me a few cycles down the road you will remember something or symptom that as happened before and wonder how you handled it last time.good luck and let me know it goes.Mark*marklingao* says on October 11, 2010 at 9:53 am

> Thanks and yes ive kept a diary from the beginning of appts and things also fully intend to keep a note of everything. Got all my ginger beer, ginger for juicing, mouth ulcer stuff in lol… Get my wig fitting today and have bought loads of wacky hats. Im going to beat this and ive told my family to kick arse if i get down. We just got to keep on trucking. *sallie* says on October 12, 2010 at 9:54 am

my story so far. *Posted on:* **October 7th, 2010** *by* **sallie**

The horrors of all horrors finding a lump under my arm an axillary lymph node. I went to the GP at Mount Plesant Health Centre on the 23/06/10. My usual GP wasnt available so i saw a junior doctor. She examined me and said i dont think it is anything to worry about its moveable and feels sort of stretchy although hard. We will take some blood test come back and see me in a week. Never gave it another thought. The week was up and I went back. No its nothing sinister, the blood tests are fine your kidney, liver function,blood counts all quite fine. Ive spoken to 5 other senior GP and they say its just a lymph node come back in 3 months or maybe before if your worried. Fine i thought nothing wrong with me.After a month the lymph node hadnt gone down and i thought this isnt right so went back to GP again my own not available and saw another jumior doctor, who looked at it and asked immediately for another opinion the senior GP took one look and fast tracked me to the hospital for a biopsy.On the 07/09/10 my nightmare started i was diagnosed with adenoe carcinoma of unknown primary otherwise known as CUP cancer or Occult cancer. This meant the cancer had spread to my lymph node but also they couldnt find the primary site of the origional cancer. This has meant they have had to send me for so many tests to try and find that primary site which sort of leaves me in no mans land and no treatment until all tests complete. I have had a CT scan that shows nothing and have an MRI scan on Tuesday 5th October 2010 which they hope will show up the primary. Now you would think its good not having a primary but it really is bad news as they dont know what they are treating so as the lymph node is clossest to the breast they will treat it as breast cancer, they cant operate because they need to use the lymph node as a tumour marker as they have no primary tumour to work with.I get the results of the MRI on Thursday so I pray they find a tiny breast cancer. On Friday i meet with the oncologist team to set up my chemo regime.I will update on here as we go along. The worst thing has been the emotions along the way. Thinking your going to die any minute, the what ifs, waiting for results. I am so lucky to have Terry who keeps me positive and trucking forward. When we found out we just held on to each other and cried all night. Some good things have come out of this like the new found love for each other that is so much deeper for the experience. Also my Neighbour Deborah Dorman who introduced me to Brandon Bays Journey and without whose help I would have lost my mind.5/10/10 Had my MRI scan today that was hard to lay still for 40 minutes. I dont think ive ever been still for 40 minutes. Results on Thursday.

> Completed radiotherapy all went well and now having a few heart problems with herceptin my LVF dropped 10% have mild mitral regurgitation and moderately dilated left atrium. I have asked to see a cardiologist to discuss this before completing my herceptin. The oncologist has said it will be fine to continue but i dont see an oncologist as a heart specialist so i will just double check. Not taking any nonsense from them. I also sadly have to report that my partner has been diagnosed with non small cell lung cancer last week at least they have a curative intent with it and its a whole new story of unbelievable cock ups that we have had to battle. Im beginning to wonder if cancer is catching, we were sat waiting to go and see his surgeon when my vet sat down beside us he had just been diagnosed with cancer, my other friend had been diagnosed with thyroid cancer, my cousin is being operated on for possible thyroid cancer. It just goes on and on. On a brighter note i now have ten patterdale terriers and they keep us very busy. Love to you all. *sallie* says on September 6, 2011 at 9:12 am

In the dark. *Posted on:* **September 9th, 2010** *by* **marknwendy**

Difficult to know where to start here. Some two months ago my wife Wendy had some discomfort in her abdomen and we went for tests in a clinic in Malaga (we have been living in Marbella for 22 years) Tests discovered extensive tumors across the liver and also in several bone areas. At that point we were informed it was 4th stage and secondary. They carried out extensive tests but came up with no primary. To be frank we didn’t place much importance in this and it was only until yesterday that I stumbled across the CUP condition on the Macmillan site. We had no idea of the significance in not identifying the primary point. The Macmillan information was a revelation on the one hand and sobering on the other.We are fortunate in that we have good medical insurance and have the leading oncologist in Spain looking after us. Unfortunately as with many such professionals in Spain they are notoriously bad when it comes to sharing information and I suspect even more so in our case.I now understand a lot more but still very much feel we are in the dark. The prognosis really doesn’t look that great…Wendy is only 51 and up to recently has led a very active life as a yoga teacher, so physically and healthwise she is well prepared to manage her condition. During the first few weeks we looked very seriously at a number of alternative treatments in Europe.Some were outrageously expensive and one would suspect taking advantage of the situation. In the end we decided to go down the traditional route and to support it with a diet that she has in effect being following for years with green juices, wheatgrass shots, high fiber and a range of supplements.We have just finished the first cycle of chemotherapy (cisplatino and gemcitabina). I guess the first few days are typical in terms of side effects..pretty yuck!….Ironically the liver doesn´t seem to cause much of an on going problem other than discomfort as it impinges on other organs (its a kilo plus larger than it should be). The bone tumours however cause constant pain , sometimes extreem, so need to take some fairly heavy duty pain killers.We are also due to have some radiotherapy next week, apparently to ease some of the bone pain…So there we are, the word paliative has been mentioned but what this means in our case is a mystery…Are we looking at months, years,,? what kind of quality of life..we don’t know. All one can do is resort to the internet (which the doctors advise against!!) and thats not exactly encouraging.On a day to day basis we manage to keep a positive attitude. Our family and children (18 , 21,) have been great and we have made the most out of what has been a lovely summer..lots of laughter, friends etc. We even recently managed a 10 day holiday back in Ireland.I would be very interested to hear from anyone that might have experienced similar conditions or any advice/insight re whats on the horizon….I know there is no exact rules but is it really best just to clam up as an alternative?? Am far from convinced personally…… Mark

Thank you *Posted on:* June 10th, 2010 *by* jo2

I just wanted to write a quick thankyou to Jo's Friends. I turned to this website last November after having been diagnosed with CUP. At the end of May last year I found a lump in my right armpit and went straight to the GP. My blood tests came back normal so I was sent for a biopsy which showed cancerous cells. After two surgical biopsies (they removed the wrong lymph node to start with) and various trips to the haematologist they finally diagnosed CUP in November. They believed the primary site to have started in my breast so I began chemotherapy treatment for breast cancer starting with 3 x FEC and 3 x docetaxel.In the meantime I was fortunate enough to get the private Cancer Type ID test done through Lab 21, details of which I found on this site. It came back with an 89% probability to be breast cancer. It was a huge relief to finally know what cancer I have and know that I was receiving the correct treatment. I have since had surgery to remove all the lymph nodes in my right armpit and am currently ungoing radiotherapy on my breast and supraclavicular area.Without this website I don't think I would have found out about the cancer typing tests and I would still be uncertain I had been receiving the correct treatment. At least now I feel I have a real chance of being cured.Joanne x

Hello *Posted on:* April 9th, 2010 *by* Deenie

I found this site a few months ago while searching for information about CUP. In July of 2006 my youngest daughter, Alison, was diagnosed with CUP, something I had never heard of. She was 27 at the time, married with a 7 month -old son and living in Florida. She and her son and husband moved back to New Jersey with me to begin treatment and have the support of friends and family. When we left Florida a doctor said to me "if you believe in God, pray." At that time I knew that she was probably going to lose this battle. Alison lived another 1 1/2 years. I have been reluctant to post his message because I never want anyone still in this fight to lose hope, and there is always hope. CUP does not respect any ages. It has been 2 years since she passed, and I am still trying to make sense of it. What would she want me to do? I would want want to raise awareness here in the states, but I am not sure how to do this.Thank you for listening to Alison's story. There is much more, but that is all I can share at this time. Alison's Mom in New Jersey

How do they know you're well? *Posted on:* March 28th, 2010 *by* marian

Hello All Any advice? Very briefly, In June 2008 I found a lump in my right arm pit. An excision biopsy at the end of July, revealed that 5 out of 25 lymph nodes were cancerous. From then until the end of september I had mammograms, a CT scan , 2 MRI scans, a bone scan, a PET scan, various blood tests, ultrasounds and an unforgetable gastroscopy and still no sign of the primary. (My Dad suggested – hoped? – that they'd mixed up my biopsy results and that I was OK). In the end the MDT decided to treat me for breast cancer. After six cycles of chemotherapy, I had a mastectomy on the 14th March 2009 – still no sign of the primary – and I finished radiotherapy on the 29th May 2009. Maybe not so brief!I returned to work (I'm a teacher) in the second week of June 2009 and at the moment I'm still trying to restart my life. But every so often I keep running into the brick wall of CUP – and getting over the wall never seems to get easier.What I find difficult is that before I started the treatment, I asked the oncologist 'how can you know that I've got cancer?', as apart from the obvious – the secondaries which had been removed -all my tests and scans suggested that I was healthy – exactly the same way that I appear nowSince then I've had three appointments with the oncologist – and he says that I'm clear – but how does he know? (A quote I heard not long after my diagnosis sums up the dilemma – absence of evidence, is not evidence of absence.)I know that I'm very fortunate to be in a position to be posting this story, but 'moving forward' is so difficult because of the ever present uncertainty of whether I'm healthy or not. Maybe I'm missing something that everyone else 'gets', so any advice about how you're coping after treatment would be welcome.Marian.

> Hi Marian – I was hoping someone would respond to this who was better able to comment; but I also don't want you to think that noone is "listening". I'm sure others will respond but I've always been

baffled that it is not possible to tell easily whether someone has or has not got cancer from something really simple like a blood test.I suspect its not in doctors interest to do this even if it were possible as the worried well would innundate the health service. I guess also that cancer is such a wide term and such a prevalent (and increasingly prevelant) disease that guaranteeing one is free of it is almost impossible. The health service view looking forward is that it is becoming a manageable disease (a generalisation). Certainly for elderly people it is often the case that they have a cancer that is so slow -growing that it is better left. One thinks of prostate cancer for example where it is often divided into tiger or pussycat to determine whether to watch or to intervene.I realise that this does not help much to overcome your very understandable fears after a very real experience.(Personally, I had malignant melanoma some 25 years ago which was caught in time but I obviously now know that I have had DNA damage. There is this 5 year survival point of a cancer experience that doctors see as a milestone but as everyone is different it is a bit artificial.)Sorry for such a long and waffly answer and I hope someone with recent relevant experience will challenge my response or give you other views. My guess is that the bottom line is that you won't have the security and peace of mind that you'd like; and it is really important to keep listening to your body and having regular medical checks.*john symons* says on April 3, 2010 at 1:45 pm

Hi Marian,My Mum has just been diagnosed with CUP with secondary bone tumor which radiotherapy has destroyed. Like you blood work, all six full body scans, lymph nodes all clear showing no signs of cancer so guess my mum and I are struggling to accept that she is poorly and how can she still have cancer when nothing is there especially when we have just been given her "expected survival statistics."I hope you find the answers your looking for I keep hunting for information and to be honest this website has given me some hope that my mum will get out of hospital and get back to having some quality of life (unfortunately she fell in hospital and broke a bone in her neck which has hindered her discharge)Take Care and I hope you get some of the answers you're looking forJennie x*jennie275* says on June 9, 2010 at 1:48 pm

Hi Salli Chemotherapy wasn't as bad as I'd imagined it was going to be. My biggest fear was being sick – I was lucky and this was really well controlled. In the end it turned out that I should have been more worried about becoming more than a bit scatty! I once got the timing of the pills I was supposed to take before treatment wrong and ended up running around the flat at 4am, seriously thinking that it was a perfect time to be doing the cleaning and even considered that redecorating was a good idea (apparently the pills can make you a bit 'hyper'). I didn't know (and never knew) if the chemotherapy was working! Nor did the doctors – as there was nothing to 'measure'. However, its almost 2 years down the road since I finished treatment and I'm still OK. I'm currently on the waiting list for a reconstruction and this is the first time in a long time where I feel as if I have any control over my own life. I hated 'handing-over' to the doctors, but I had no real choice.Please feel free to ask any questions – there doesnt seem to be that many people to give us any answers! But – what did you call the wig? (I found mine itchy and used 'Buffs' instead – cool head wear for the fashion concious bald person – you get them in 'outdoor' shops like Millets)Keep wellMarian*marian* says on October 14, 2010 at 1:51 pm

Hi Marion,My worst fear was sick as well but it does seem ok with the pills, i do feel trembly like you say a bit hyper…..My wig is chucked in the cupboard i think its called the RAT…. i dont much like it and love the hats i got from America they are so much more in front of us. I also bought hats from Accesorize in town expensive but loverley.I suppose i am lucky that they have the lymph nodes to measure my chemo by or so they say thats there tumour marker to tell if its working. They have told me they are actively looking to cure my cancer now that they know ther is no sign of any other cancer in my body which is brilliant when they said it wasnt cureable. I suppose they will never say its cured as such because of the no primary. I am confident my primary has already gone.Im so glad your well and staying that way. Its hard i should imagaine when you are on your just going back for check ups in the first instance you must worry about every feeling. 🙂*sallie* says on October 16, 2010 at 1:51 pm

Hi EveryoneJust returned from my 6 month oncology appointment.I hope you are all well – as I am – as a very, very green registar informed me. It was only after I prompted her to actually read my notes that she wrote up another blood form. 'oh! you had all your lymph nodes removed and 5 of them had secondaries – well for people like you we usually do continue the blood tests'. Apparently the best course of treatment is for me to develop some more metastisies (if the spelling is OK) and then they will have another go at guessing where the cancer is. I expressed surprise that she scheduled my next appointment for a year on (I guess most people with 'normal' cancer would be thrilled at such a long leash) and she went off to find my new consultant. What do I do? I got quoted the NICE guidelines for treatment of breast cancer and was told that since my now retired oncologist had treated me for breast cancer, that was the plan of action. I'm happy that I'm apparently 'well', but I'm totally unconvinced that I'm going to stay that way! The new guidelines – they don't go as far as 'what happens if the patient is so lucky as to actulally survive.'Man – that was really depressing!Marian*marian* says on January 5, 2011 at 1:52 pm

Doesn't sound too comforting. As a layman I would have thought a year disconcertingly long and they should be "preventing" not waiting for "metastasis".
My only thought, and others may have better ideas, is to ask for a review by the CUP Team quoting the NICE CUP Guidelines. (If they can quote Guidelines, so can you!) See this page for access to the Guideline http://www.cupfoundjo.org/diagnosis_and … t/nhs.html
It may be that your hospital have not followed the NICE Guideline and don't have a CUP team (yet). I think what you could still try to get at is: how convinced they are that you are no longer a CUP patient but they are confident that it is Breast (what is their level of confidence?) . The aim is always to get a CUP into a recognised site specific team for treatment but you need confidence that this is the right diagnosis.My guess is they might be rather dismissive but if you make a bit of a fuss at least they'll see you again (perhaps someone different) and you can press for more regular testing. What does your GP advise if anything? Sadly, it seems necessary to make a fuss sometimes and the bottom line is that they must communicate effectively with you and give you confidence in their treatment plan. No decision about me, without me is now the great cry.*john symons* says on January 6, 2011 at 1:54 pm

Stir them up Marion, firstly you are entitled to a second opinion. Ask to see your notes it always unsettles them, you will have to write to ask to see them but once they realise your checking up on them they dont much like it and bend over to do what you want. DONT take NO as any sort of answer. If your still not happy make a formal complaint stating why you feel so worried and that all your asking for is some re assurance. They wont like it but hey your not out to make friends with them, ive battled my way through the blocks and have found that they do just about as much as I expect from them. Good luck and keep us posted.*sallie* says on January 6, 2011 at 1:54 pm

Hi Marian,Sorry I took so long to respond.Trying to catch up with everything thats going on around me at the moment.Yes ,I agree with Sallie and John"s comments. You should push for an explanation that assures you.I dont think that you should have to wait another year. I dont think anyone with any cancer should have to wait a year if there are any doubts. Keep on top of it and dont let them fob you off. I am glad however to here you are feeling better and wish you all the best. (Jim and Betty)*bewildered* says on January 30, 2011 at 1:56 pm

Hello AllThank you for the 'fighting talk'. It inspired me to write a letter to the Patient Advisory and Liason Service – and I got a fantastically inadequate reply. So I wrote again – a letter I'm very proud of – and got an appointment (within a week) with the CUP doctor. Although he wasn't especially convincing, the stats he showed me were. I feel slightly easier about the long term prognosis, but I still have many concerns and I am currently awaiting a reply from PALS. (Do I need blood tests? Is a year appropriate? Do you consider the imact of a CUP diagnosis on a patient? Did you read my notes? Did you understand my notes? Do you know what you are doing?)No date set as yet regarding the reconstruction – cut backs I reckon!

> On a weird note – I was contacted by the BBC (The One Show) who wanted to film my reconstruction as part of a story about the 'fantastic' surgeons at The Royal Free in Hampstead – I considered it briefly, but since the story was about their brilliance and seemed to give little room to 'My Story' and I couldn't face a classroom of 16 year-olds who have seen a more 'private' side of my life – I said 'no'. I wonder if that had an effect on the delay!I'm OK at the moment – as I hope you all are – and I'll keep you posted.Marian*marian* says on April 4, 2011 at 8:03 pm

HELP!!My mom has been given a few months… *Posted on:* March 22nd, 2010 *by* devastateddaughter

Hi everyone, I am new to this site and am soo happy to have found this site. My mom has just recently (Feb 8, 2010) been diagnosed with CUP 😕The cancer has spread to her liver, lungs and abdomen. I am very depressed she is only 54 years old and the oncologist said that he gives her a few months if the chemotherapy does not work and maybe a year if it does work…Basically, both scenarios suck it's just that one is better than the other, i guess.He said that it is a very aggressive cancer and they started chemotherapy Feb 19, 2010. She is being given taxol/carboplatine. She has done 2 treatments so far. The first treatment the doc said her body responded well and she tolerated it well but could not say anything more…I am really really devastated and was wondering if anyone could help me or share a similar experience…are there any happy endings? Is there anything more we can do? They did not do a pet scan cause they say it's too expensive and since she is stage 4 they rather use the ressources on someone else (canadian system)…would doing a pet scan in a private clinic (costs $2500) be a added value to maybe find the primary???Thank you for listening,
Emily

> Hi there,Sorry to hear about your mum. My mum was diagnosed two weeks ago after been ill for months with CUP. Like you I'm desperately trying to find more information and trying to understand this disease because I had nerver heard of it.We have been told she has a 30% chance of surviving which is still sinking in as I'm still in the denial phase and really struggling with how can you only have a survival rate of 30% to a cancer that you can't find? Especially when the radiotherapy had destroyed the secondary tumour in her hip.Keep positive and this site is great,knowing there are people out there going through the same thing ais really helpful as I have felt really alone over the last few weeks.Jennie x*jennie275* says on June 9, 2010 at 10:03 am

I Need Some Questions Answered – Can You Help? *Posted on:* February 24th, 2010 *by* Janeb

Dear Friends I was diagnosed with metastatic neck cancer, unknown primary in February 2009. Finding this website has been my lifeline.After surgery and radiation I really began to research CUP and was utterly astounded by its invisiblity in Australia. As a health professional I decided that something needed to be done about this. CUP only features in the statistics. CUP in Australia is defined by the word 'lack' – lack of research, clinical trials, patient information and support, clinical guidelines, specialist clinics and pracitioners, lack of any representation, lack of public awareness, lack of a great website like Jo's Friends.I have been in contact with key people and organisations around Australia. John gave me the encouragement to start to change things and now people are begining to talk about this cancer. I need your help. I have not spoken to one person to date who has CUP.1) Can you suggest any strategies to contact other CUP survivors in Australia? I want to form a lobby group to push for a better deal for those of us with this diagnosis. CUP voices need to be heard. I have been unsuccessful to date despite putting my story on the web and through an article in the patient representative e-newsletter – no replies to either.2)Do people in the UK actually get given a CUP diagnosis? I was told the primary could not be found and gradually, through my research, came to realise there was a group I fitted into – CUP.3)How visible is CUP in the UK in terms of public awareness, knowledge of health care workers, availability of patient info etc?4)Are there any CUP-specific clinics/specialists in the UK?Maybe that's enough for now. I'd love to hear from you.

> Let me start by picking-up on Q2 and hopefully others will join in to answer your excellent Qs.Cancer of unknown primary (CUP) does not have a discrete classification within the International Classification of Disease (ICD) . The ICD codes which will usually cover registrations of CUP are ICD C77 to C80. Unfortunately, as there is no agreed definition of CUP, these codes may not capture CUP, or people may be included within other ICD codes.C77 Secondary and unspecified malignant neoplasm of lymph nodesC78 Secondary malignant neoplasm of respiratory and digestive sytemsC79 Secondary malignant neoplasm of other sitesC80 Malignant neoplasm without specification of siteI know this is a somewhat technical answer but guess that you are used to the way hospital events are captured.This poor coding is part of the problem.In reality I guess that many older patients, particularly those with co-orbidity who are not fully investigated, will not get labelled CUP for simplicity. I guess that some patients will be given a mets diagnosis in the hope that a primary will be found quickly; and some will be told about CUP. I have sensed a reluctance to use a CUP diagnosis as it can be seen as a failure of diagnosis and doctors, like all of us, don't like to be seen not to be able to answer the questions. So CUP has been swept under the carpet for too long! It should be a diagnosis in its own right otherwise patients will be marginalised.The NICE Guideline on management and treatment of CUP that is coming out for England and Wales (end July) will increase the visibility considerably.It should help the diagnosis issue by establishing better hospital event categorisation but it will have no impact on the ICD codes that need WHO to change them. How does that happen!?*john symons* says on February 24, 2010 at 11:40 am
>
> I can understand your frustration, trying to find other CUP patients. I contacted our Cancer Society (Canada) and waited months before I received a phone call from British Colombia. I live in Ontario in Eastern Canada.Yes there are survivors but it difficult to find them. I finished my chemo two years ago and to date there has been no recurrance.What did we do to survive this? That is my next question.I had the gunshot approach – three chemos at the same time. It was very difficult . In retrospect I am glad I had it.DianneAnother CUP cake*Arcticnurse* says on February 25, 2010 at 11:42 am
>
> Thanks so much Dianne and John for your replies. It's great to hear from both of you. I have been trying to get a picture of CUP in other countries such as the UK and USA and I've now added Canada to my list.Dianne, it's great to have contact with another CUP survivor. I hope you are continuing to do well.Have you had contact with any other people with CUP? Is CUP visibile in Canada? Who are the experts in your country? Is there any sort of international CUP alliance?I seem to have never-ending questions. It's my frustration at feeling so isolated!!Thank you John for all the work you do. I feel less alone when I can tap in here and also have a read of what's going on in the UK.cheersJane*Janeb* says on May 3, 2010 at 11:43 am

recently diagnosed…*Posted on:* February 8th, 2010 *by* Liz.North

I've been diagnosed with C U P: started mid November with lump under arm: biopsy showed malignancy, so was scanned [lungs, breasts, womb, stomach, bones]: nothing found; so had lymph nodes in right axilla removed: out of 23 nodes, 9 showed cancerous material. Now I'm meeting with oncology who I'm told will probably suggest capecitabine for chemotherapy. OR, on account of my age [77] they may leave the presumed primary source to show itself. Would love to hear from any other of Jo's friends who have gone along this road and if so what treatment they had and how it affected them.

> Hello Liz,hope you're ok. I've had a similar experience to you – cancer in armpit lymph nodes, no primary found. I haven't had surgery yet but have had chemo.Chemo is hard work but as long as you know what to expect you will be ok. The chemotherapy nurses I worked with were fantastic and managed all of my symptoms brilliantly. I decided at the beginning I was going to do as many 'normal' things as possible but I wouldn't suffer unnecessarily – when they gave me advice, I took it. If they decide chemo is the best option, here are some of the things I learned along the way:I did lose my hair, but it's not that bad in the grand scheme. Spend some time chosing a wig. I got the first wig

> I tried on and left the shop within 15 mins – er, not a good idea. I had to get a second one. I wear mine for special ocassions but everyone is different, I suppose. http://www.scarfhut.co.uk sell some great headscraves.I wasn't sick once, but my stomach has been temperamental throughout. I adjusted my diet to suit, and I've eaten everything I fancy because life is too short not to. However, I have made sure that I ate fruit and veg to get vitamins and minerals. If your taste goes, sometimes it does, crunchy salads with lots of flavours and textures worked for me.Your mouth, nose and eyes go funny – they become sore and inflamed. You have to be careful your nose isn't running without you realising it. I put my daughter on 'snot watch'. Just means you will always have to have tissues handy. This only lasted for a few days at a time.There is some pain in the muscles and joints – it's OK if you manage if from the offset. Take the pain killers. I tried to be brave at first – but there was no point. Get into a timed routine and stick to it because that works best. Get stronger painkillers if you need them. Again only lasted a few days at a time.I got up and washed and dressed everyday – sometimes just into my scruffy hang-about-the-house clothes – but I got up. If I got really tired I went to bed later in the day.I got in a pile of magazines, books and DVD's to watch.
> I carried out simple household chores and decided not to worry about anything I couldn't do.You can get pins and needles in your hands – it's not that bothersome, but you might drop things more while it's happening.At one point I did a lot of baking to keep myself busy.Get vitamin E oil from Holland and Barrett – it's brillant for dry skin.Now it's all over, it seems to have flashed passed.Whichever decision you make, hope all goes well for you. Take care Andrea x*Doddgirl* says on February 8, 2010 at 10:55 am

I'm a CUP cake too! *Posted on:* **February 4th, 2010** *by* **susie.ryan**

Hi all Thank God for this forum! I cried when I found it!Have to say that the immense relief that I have obtained so far from just reading everyone's stories on this site is incredible. Up to this point I have felt so very alone as no one could give me any advice, nothing to read, nothing to comfort me as I flounder in this no mans land called CUP!I am 36 years old living in Limerick, Ireland and I also have a metastatic lump in my left axilla lymph nodes- Is any one else noticing a pattern to this location for secondary sites. The lump was found on the 16th Nov 2009, (this date is now more imprinted on my brain than my wedding date, sorry hubby!) diagnosis of metastatic disease came on the 17th Dec 2009 (happy Xmas to me eh!). I was told that investigations would need to be done to find the primary. I didn't get the impression at this stage of the impending saga of trying to locate Wally (this is the primary's name at the moment, at other times expletives are used).I have had ultrasound of the breast, mammogram, biopsy, chest x-ray, ENT investigation, MRI, 2 cat scans (meow!), PET scan, gynaecologist investigation – another ultrasound due of the ovaries, Colonoscopy next week. The Breast Clinic has now passed my case to the head oncologist in the hospital for him to determine what happens next.I hate the fact that things are moving slowly, I feel that valuable time is being lost and that I have very little control over this situation because of the "uniqueness" of my situation. I hate that when I ask questions of my consultant you can see the struggle in her face to try and find words to comfort me but not give me platitudes.My father is also going though his own battle with bowel, liver and lung cancer at the moment and even he who knows the distress of a cancer diagnosis can't get his head around the fact that the primary can't be located.I am trying to keep my spirits up but as time wear's on and the gap between tests becomes more stretched out, I feel that my positivity and sense of humour is being slowly eroded. I am trying to meet this challenge head on and keep a sense of humour despite the severity of the situation. I have also received a boost from the stories recorded here to date and the fact that people have survived several years when to this point I have been told that prognosis is not something they can advise me on. This forum has proved to me that remission is possible and in some cases a full return to health can happen.Thank you for giving me the boost I needed to face in to the battle ahead.Hugs to all out there who are endeavouring to deal with this either as a patient, spouse parent or friend.Susie

> Thanks for posting Susie. Your story is all too familiar from others who have encountered a medical profession unsure of what to do. CUP patients need early involvement of specialists with CUP experience and efficient arrangements to manage diagnostic investigations to get as many clues about "Wally" as possible. CUP patients tend to be bounced between MDTs and specialists and this

causes delays which are frightening.We can’t and don’t offer medical advice but the Draft Guidelines for the management and treatment of CUP are on the NICE website. These documents are in draft because the Guideline is out for consultation to experts to make changes before the document is adopted for England and Wales and N. Ireland in July of this year. P61 of the full draft makes mention of the proposed way of handling patients with Adenocarcinoma involving the axillary nodes. If you delve into chapter 5 of the evidence review (separate document) you will find more background information that informed the recommendation.Some people don’t want to research their condition and I understand that position. If you did, then you might want to find a tactful way of ensuring your oncologist is aware of NICE’s thinking (albeit subject to change in review). Suggesting to a doctor in the “Free State” that it might be worth looking at an English document might need careful handling!To get a quick link to the NICE documents go to our front page and look at point 2 on the Message Board.I hope others will add any comments – whilst this forum is not overactive there are people who look-in and I know it means a lot to get some comforting words even if the specifics of the disease are different. Most will have experiences of the diagnostic pathway as patient or carer.Best wishes, John*john symons* says on February 5, 2010 at 9:44 am

Hi John,thanks for this, its fantastic to have something substantial to read that is pertenant to my situation.I shall gauge the situation when I meet the Oncologist and see what is put on the table.I also want to thank you personally for setting up the website and this forum, I feel empowered! 😀 Susie*susie.ryan* says on February 5, 2010 at 9:45 am

Hello Susie,good to hear from you. Hope things aren’t too bad.We do seem to be having a similar experience. My step-father is currently battlling terminal lung and stomach cancer so I know how you’re probably feeling about that.I also have had a difficult time with medical specialists who become either very meek or totally obnoxious when faced with questions they really don’t know the answer to. I’ve seen 5 different consultants in 3 different hospitals and been subjected to numerous ‘examinations’ but don’t have any clearer idea. On more than one ocassion my notes and information have not been available to the specialist concerned – this is very worrying. There seems to be a lack of coordination between hospitals and sometimes within hospitals. The ‘procedures’ are disorganised and the whole system is over-stretched. And, I haven’t actual seen anyone who specialises in this type of cancer. It’s terrifying sometimes!Am about to meet with the head chemotherapy nurse so she can talk me through the pathology report. I had to ask 5 times for copies of my notes, and even then was only given letters sent between consultants, not actual reports. I still feel that there are huge gaps in my knowledge of this situation. I’m not sure if that’s because the medical team really don’t have any answers or they are reluctant to discuss particular issues with me. I stopped asking questions for a while because I was getting such a hostile reponse and I was too tired to fight over it. I have sometimes felt as if I’m being treated like a nuisance child – but now they want me to make this ‘decision’ and I’m not sure what to do. I don’t have much confidence in the information I have because it’s been so confusing and every time I ask for clarity it seems to be construed as a personal insult.Having said that, I have just come through the chemo, which I tolerated reasonably well and the chemo nurses were fantastic. I am hopeful about everything.I hope you get your ‘answers’ from your oncologist in your next meeting. Stay in touch. Andrea x*Doddgirl* says on February 8, 2010 at 9:48 am

Oh dear, that was a bit of a grumble, apologies Susie.I should also say, I know how you feel about waiting – it can leave you strung out and exhausted. It took three months to get a treatment plan for me. This is at least a month longer than NICE guidelines suggest for cancer patients. However, in our cases it is probably best to use as many investigations as is sensible to narrow down possibilities because it will influence the treatment plan.Whatever is decided for you next will be the ‘best’ that your medical team can offer and if they have carried out investigations and surgery, they do have a lot of information. I’m sure the whole process will get tighter and faster when enough CUP patients present themselves.Apologies again for off-loading like that – it’s not all bad.Hope the near future brings you good news.Take careAndrea x*Doddgirl* says on February 8, 2010 at 9:49 am

Dear Susie – apart from the fact that I'm more than twice your age, we share same symptoms: axilla nodes, scans etc. Except that you had a colonoscopy. I did ask oncology teams etc about that and the answer came: cancerous nodes in the top half of yr body don't come from lower organs. Ho hum, but I keep asking. Am heading for chemotherapy: the AC Combination which is apparently safe for my age group.From what you say I guess that, like me, you feel well physically but mentally all over the place: whom does one tell? And when one tells, people say: 'but you look so well!'. The diagnosis takes over: medical appointments fill up the week. Work [I'm a freelance writer so not fully retired] shrinks away.Would love to hear from you. And all very best wishes. Liznorth.*Liz.North* says on February 13, 2010 at 9:52 am

Hi SusieI'm sorry to hear you have joined the club but dont let yourself get "down".
It takes a fighting spirit and some humour to get through this.I remember doing research when I was told it migh be lymphoma. Then it was the waiting game. For the longest time I thought the primary was just an illusive "ghost"No one mentioned CUP until I had started Chemo but by then I was too ill from the side effects of the chemo to think about it.But the chemo was working within two treatments The lymph node was shrinking. Then I started to do some research. The Canadian statistics were horrible. But these were other peoples numbers not mine.I proudly wore my "I'm too sexy for my hair" T-shirt and had my bald head tatooed with henna flowers.I completed the chemo after 6 treatments. That was April 2008.It was about that time I found this site. I thank John and Jo Friends for this wonderful site. It has made me feel I am no longer alone in this journey.I had and opportunity to meet him at the Conference in October.Dianneanother CUP cake*Arcticnurse* says on February 21, 2010 at 9:53 am

Hi Allapologies for not updating sooner.To bring everyone upto speed, I have started treatment woo hoo!The past couple of weeks were somewhat hectic, a lot of sudden activity and then starting the treatment plan and then getting my bearings with being sick and managing the side effects (prior to this my most serious aliments ever has been occasional migraines and a dodgy stomach! So truth be told I have never really had a very sick day in my life!)Anyway, the results of the biopsies from the colonscopy and endoscopy came back negative as was suspected.It has been decided to treat me like a breast cancer patient as per the recommendations / guidelines. So I'm on AC/T which runs as AC every 2 weeks for 4 go's and then followed by Taxol every 2 weeks for 4 go's, this brings me upto the end of June. Where they will assess my lump and determine how much radiotherapy they will do and then onto surgery to remove the lymph nodes.I have just completed my 2nd chemo yesterday and it went well all things considered, hair loss has started which means I need to get my ass in gear and sort out the wig (better to have it and not want it, than want it and not have it!)The acid reflux, nausea, headaches & pains and extreme coldness are possibly the worst side effects only for once you manage to get one under control another becomes more prominent but at least I am well sorted for how to handle things this week when they kick off.The most important update that I have for everyone is that after just 1 chemo treatment the lump has reduced from the estimated size of 7.5cm to 5cm. Happy days and so comforting as its proof that the treatment is working!

Andrea ~would like to say a special thanks for the link to the http://www.scarfhut.co.uk website as they have plenty of stylish options and I got to say over here the shops just don't have a decent selection of styles or fabrics. I am well and truly sorted for scarves now. Also no need to apologies for grumble as I took it as adding to the pool of info.Part of me has been very frustrated by the number of tests that have been conducted, however my biggest bone of contention at the time was that once the tests were conducted by depts outside of Oncology the urgency was not there, and the efficiency element was lost were multiple tests could have been conducted closer together or even simultaneously.However on looking back I am thankful that so many tests were conducted as there is an element of comfort to be taken from the fact that they have searched for the primary high and low, as I know that I personally would have been uneasy about starting any treatment if all stones had not been turned over.Liz~ from the extensive conversations that I have had with various consultants and specialist nurses I have also been told the same thing that if a secondary appears in the axial nodes the primary will have originated in the upper body, however they did do the head to toe search for me, and I think we are all the most knowledgeable about our own bodies and if you feel that there is a particular part of your body that may perhaps be giving problems then I would most definitely pursue it.Dianne~ I firmly agree with your statement that the statistics are some other peoples numbers. And I also subscribe to the fact with statistics that even when the percentages are dismal and suggest 80% failure, I think that there's 20% for whom it was not a failure and I can be in that statistic, someone's got be, that's the way I look at it.Maggi~ I'm very sorry to hear about your diagnosis. And I like everyone else, who follows these stories wish you the best of luck. It's a perfectly natural reaction to feel overwhelmed by all of this as I am a firm believer in the knowledge is power principal and the full knowledge of our situations is elusive and that for me personally was the hardest thing to accept. With regards to planning you can only deal with the here and now. I am subscribing to short term planning when asked by colleagues when they can expect to see me back at work and how long this will go on for, and my answer is short and sweet- I don't know and this is time for me to prioritize me now. Hang in there and remember that you are not alone and avail of the support of people on this site and support groups in your area as well as the counseling services within the hospital.On a final note to all I hope that you are all doing well.HugsSusie*susie.ryan* says on March 16, 2010 at 9:54 am

Hi ThereFor the first time I can finally say "I know what you are going through". I had a lump in my right groin.I have been a fan of Jo's Friends for almost two years.
It is two years since my chemo and I still feel great. Too great as I'm gaining weight again. Eating too many cup cakes.I went to the CUP conference in London last October.I was sorry that there were few survivors there but it was interesting.I am happy that there is sharing of research from the US & Europe.I love checking this site and am interested in new postings.Thank you John.I celebrate each day and make Cup Cakes when asked to bring treats to functions.DianneThe Canadian Cup Cake*Arcticnurse* says on March 16, 2010 at 9:55 am

Well done Susie – great stuff! I'm not a fan of statistics when it comes to CUP. There is simply insufficient knowledge and data for accurate epidemiology. I agree too about listening to your own body. The medical profession rely too much on site specificity, I think. CUP tumours and/or the spread behave differently – about all we know – and assumptions that a secondary in one particular part of the body means the primary should be coming from some particular area is based on known primaries. That's my non medical view!Thank you Dianne – good to hear from you too – delighted to hear good news.*john symons* says on March 16, 2010 at 9:56 am

HiI'm back again! 😀Just a quick update as to where things are at with me.I just celebrated my 37th birthday yesterday and was reminiscing back to Xmas 09 and my thoughts and fears that I would not reach my 37th birthday and am glad to say I'm here and have no intentions of giving into this demon! I celebrated last night with a few glasses of champagne and a fabulous Margaritta!Well I finished Chemotherapy about 7 weeks ago and since then I am trying to get the old engine running again and boost my energy levels, if anyone has any tips out there on things I can do I would really appreciate it (i can stay going now for about 3 to 4 hours but after that I'm like a zombie), I know they say that it will take a while for the energy to come back but I have to say I havent the patience to wait!I am now officially about to embark on what I have deemed to be stage 2 of my treatment, which is the operation. At previous chemotherapy sessions various doctors were mentioning mastectomy however I am glad to say that my consultant in the breast cancer clinic has been very confident in stating that there would be no advantage in having a mastectomy as it still remains an unknown as to where the cancer originated (despite ongoing investigations in the gynaecological area). At this point i must actually post a warning to others who are in a similar situation to myself that should other units want to conduct various invasive tests while you are on chemotherapy please let your oncology team know and get their advise on whether or not to proceed with the test(s) while on chemotherapy, as the risk on infection is greatly increased.So my surgery is taking place on the forthcoming wednesday 28th July and they are going to do a left axillary clearance and to all intents and purposes i believe this is a very straight forward procedure. Following that 6 weeks later they plan on starting me on approx 5 weeks of daily radiotherapy. And then…. well we shall wait and see.Oh and I have one final question for those of you who have already gone through chemotherapy, has anyone else experienced issues with their eyes! I am constantly getting infections in both eyes for the last month and frequently have swollen eye lids (have done a fair bit of research on this on the internet but nothing helpful has turned up). Oh and how long does it take for your eyelashes to grow back???Hope everyone is doing good.Hugs to allSusie XXX*susie.ryan* says on July 23, 2010 at 9:57 am

hi Susie
The energy will be "on hold". Take it slowly and review your levels in 3 months. I'm 3 months past the two year finish of my chemo. I'm full of energy in the morning but still wilt in the afternoon so I plan my day around it.Everyone tells me I look great. I just smile.I recently enrolled in an exercise class and am working at shedding a few pounds.Keep on fighting.Dianne*Arcticnurse* says on July 30, 2010 at 9:58 am

By the sound of it im lucky to be diagnosed after the NICE guidelines came in and my scans etc have been as fast as they could be over a couple of weeks. I should be starting treatment next week. Also for anyone interested i gained great strength and inner peace during the waiting periods of darkness by using Brandon Bays journey. I feel that i will be ok more so because of my inner peace. http://www.thejourney.com/welcome.htm *sallie* says on October 7, 2010 at 9:59 am

Hi All,Just a very quick note on where things are at with me.Had my surgery back at the end of July and all went well, only set back had at the time was about 2 weeks after surgery I ended up back in A&E with an infection which had me hospitalised for 4 days but I recovered.I just started 5 weeks of radiotherapy this week and all is going fine with that as well, tired but thats nothing new.On a more sad note, my father lost his own battle with cancer on the 16th September and at least there is no more pain for him now which is the most important thing.Hope everyone out there is doing as well as possible under their circumstances.Susie*susie.ryan* says on October 14, 2010 at 10:00 am

CUP Tumour found in axilla lymph nodes *Posted on:* **February 4th, 2010** *by* **Doddgirl**

Hello, thought I'd share my story in the hope that it can help both myself and others understand more about this condition.I'm a 39 year old female and live in Stockport, UK.I found a lump in my right armpit in May 2009. Following a series of tests which included: 4 ultrasounds, 2 MRI scans, a CT scan, a PET scan, a biopsy of the lump and a second opinion of the biopsy, still none the wiser as to the origin of the cancer. All I know is, 'it's aggressive'. A second cancerous lump in the armpit was identified through the CT scan. Fortunately, no other lumps or bumps have revealed themselves in other parts of the body.Situation became very confusing when an MRI scan in Macclesfield (a centre of excellence for breast cancer) showed a 'vague 7mm thickening' in right breast. But, a second MRI scan in Bolton (which has the more advanced MRI scanner) reported no such finding. Was it there, or not???In all, it took from beginning of June to beginning of September to decide on treatment plan.Oncologist decided that given the location of the 2 tumours, we'd follow a treatment plan for breast cancer.I've just been through 8 rounds of neoadjuvant (pre-surgery) chemotherapy (4 FEC, 4 Docetaxel), given intravenously every 3 weeks. The second tumour has responded to chemo and has shrunk by 6mm.Will be undergoing surgery to remove all the lymph nodes under my right arm. Have been offered a mastectomy or radiation therapy to the right breast – BUT, as there is no comparative data available to determine which option would be most beneficial, the decision has been left to me. Oncologist thinks mastectomy would probably be the best option, but surgeon suggested radiation therapy may be sufficient. Do I have a mastectomy or not???? I don't know which would be best, and have until March 3rd to decide.I hope this email finds all of you who are having this experience having a good day, today. If you're having a simiar experience would love to hear from you.Take care, Andrea

Hi AndreaI too like you have a similar story however I am not as far down the road as you are.I can't even begin to imagine how it must feel to have to make the decision that you are currently facing. I can only offer you the following advice:Have you the option of availing of a 2nd opinion within the group that are taking care of you, perhaps the oncology nurses can advise you based on their extensive experience of the implications of both options? Perhaps the hospitals clinical psychologist / counsellor can offer some assistance to you while making this decision. I personally have started to poke the brains of all individuals that I have encountered and some of the information i have obtained has assisted me to date.I wish you the best of luck with your decision making.Susie*susie.ryan* says on February 5, 2010 at 10:49 am

Hello Doddgirl Your story is the mirror image of mine (same age when it all started too), except that I'm a year ahead of you – so that's good going! At the end of june 2008 I found a lump in my right armpit and was referred to a haemotologist (previously I'd had another lump investgated by FNA and was cleared) and she recommended an excision biopsy – this happened at the end of July. Everyone thought that I was going to be OK, but the surgeon straight away began to prepare me for 'bad news' – 'your lymph nodes were a bit sticky, so I took them all out' and they were sent for biopsy. They tolld me that of the 25 removed, 5 were cancerous. From then until the end of september, the hunt was on for the primary – same series of scans and tests, but no sign of it – although the team caring for me were all convinced that the primary must have been the breast.The suggested treatments were, mastectomy, chemotherapy and radiotherapy OR chemotherapy, mastectomy and radiotherapy OR chemotherapy and radiotherapy! From such a huge range of choice I chose chemo, mastectomy and radiotherapy. For me, my primary concern was 'getting' the cells that may have escaped during the period I was being 'investigated' and then I felt that I wanted to get rid of the most likely cause of the secondaries.I came through the chemo (3 FEC and 3 Docetaxel) bald, but loving 'buff's' – trendy headscarves which I got from outdoor clothing shops. And then the mastectomy on the 14th March 2009 – still no sign of the primary, which strangely, was a bit disappointing!A year on and I'm still clear (apparently) and I've already had an appointment with a reconstructive plastic surgeon. I've returned to work and have blood tests and oncology appointments every four months. I have no regrets about the decision I made and I hope that you will feel as good about the choice you made.Good LuckMarian X*marian* says on March 16, 2010 at 10:51 am