

'Treatment' section transcripts from the old Forum (called Meeting Space) –edited

Years 2011 -2013

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Coal face posted on: June 25th, 2013 by John (Moderator)

I've recently come across a blog that some might find helpful. <http://coalfacecaring.com/> Clinical psychologist Sidney Bindemann writes about the cancer patient's 'journey', with explanations of treatment such as radiotherapy and chemotherapy, adding some very wise words of advice based on experience. I found it good but interesting to see what others' think.

Trying to understand the treatment options Posted on: February 12th, 2013 by John (Moderator)

Personally I think that integrative approaches to treatment have an important role in treating the cancer patient but it is hard to know what is valid and what is 'snake oil'. I've come across this company recently. Cancer Options is a private consultancy where (for a fee) you can obtain guidance on orthodox, complementary and integrative cancer treatments and therapies. <http://www.canceroptions.co.uk/> I'm not in a position to endorse the consultancy's work or otherwise, but we try and make available resources that may be of help and let people make up their own minds. If anyone has experience of Cancer Options or have views on complementary approaches please share your views.

John, Mindfulness may be of interest. It is being used by several health trusts currently as 'complementary' therapy for both patients who have just completed a course of treatment and their carers. The techniques and methodology were developed at the University of Massachusetts Medical School to assist patients with chronic pain. After Mel, my wife, had completed her first chemo treatment regime, she and I followed an 8 week Mindfulness course at the Health Trust's Cancer Centre. We found that the techniques to ease and alleviate stress enabled us to cope with the roller coaster ride that CUP treatment often involves. Additionally, the underpinning emphasis on appreciating, focusing on and enjoying the present moment did help in alleviating the fear of the future that accompanies cancer diagnosis and treatment - particularly in the more uncertain world of CUP diagnosis and treatment. Thanks Peter

Genetic Profiling Posted on: January 30th, 2013 by John (Moderator)

The Daily Mail in England carried an article about genetic profiling yesterday and mentioned CUP <http://www.dailymail.co.uk/health/article-2269931/Cancer-longer-death-sentence-DNA-based-treatment-transform-lives-10-years.html> This is the page on our website where we show the tests that we know about http://www.cupfoundjo.org/diagnosis_and_treatment/tests.html

New Android phone app for those on chemo Posted on: November 27th, 2012 by John (Moderator)

Dr Richard Osborne of our Advisory Board, who led on the NICE CUP Guideline, has developed a new smartphone app which helps patients deal with treatment toxicity. The idea is that if patients experience, say, excessive levels of nausea, vomiting, mucositis etc, the app prompts them to contact their cancer hotline and speeds up that process. The app also helps accelerate access for treatment if potentially serious infection is present. It is called the Cancer Emergency Response Tool (CERT) - and it's available for download for free, for Android phones. It can be found by going to Google Play and searching for

“cancer emergency response tool” or see this link

https://play.google.com/store/apps/details?id=com.neutropenicsepsis.CERT&feature=search_result#?t=W251bGwsMSwyLDEsImNvbS5uZXV0cm9wZW5pY3NlcHNpcy5DRVJUII0

I’ve asked what the access plans are for those with less advanced phones (me) or tablets (the computer sort) and will let you know the answer!

[How to eat well when you have cancer](#) *Posted on: November 23rd, 2012 by John (Moderator)*

There is a new book out called: How to eat well when you have cancer, by Jane Freeman, published by Sheldon Press, London at £9.99. I know the challenges of eating, particularly when undergoing chemo. I’ve skimmed the book and think it looks very good. If anyone reads it please post a review.

[Research grant](#) *Posted on: October 18th, 2012 by John (Moderator)*

For those who haven’t seen this in our latest quarterly eNews – you can sign-up here if you want it http://www.cupfoundjo.org/support_our_work/index.html - you may be interested to know that we have made a research grant. The Trustees have been working with our Medical Advisory Board for some time to identify a suitable project. We have made a grant to Dr Harpreet Wasan (Consultant & Reader in Medical Oncology Department of Cancer Medicine, Hammersmith Hospital). We are funding a molecular profiling pilot project that aims to develop more efficient treatment and management of CUP. Molecular analysis technologies are evolving extremely rapidly, and in the last few years it has become more feasible, both economically and scientifically, to look at the DNA sequence (whole genome) of previously banked or stored tissue biopsies. The project aims to uncover potential biomarkers (predictive and prognostic) of CUP by utilising clinical tissue samples, accrued at the Hammersmith Hospital, that show hallmarks of CUP metastasis, where no primary site of cancer is identified. Next generation sequencing will be performed on a subset of the samples as a pilot that will help us to understand the disease and detect potentially “drug-able” mutations. A successful pilot will enable further research. We are not a wealthy charity and mindful of the generosity of our donors and fundraisers, and the heavy cost of research, the trustees are reluctant to make any significant research grants that will not be of the highest value in ‘making the unknown, known’. I hope that you will agree that this is an excellent use of our funds.

[Feedback on patient experience research](#) *Posted on: September 21st, 2012 by John (Moderator)*

Some on Meeting Space very kindly contributed to the patient experience research we have been undertaking for the last 3 years with Southampton University. A summary of the findings is published here http://www.southampton.ac.uk/healthsciences/research/projects/Understanding_the_unknown.page

Research study: patient and carer experiences of CUP *Posted on: December 1st, 2011 by John (Moderator)*

The CUP Foundation is working with researchers at the University of Southampton and clinicians in Southampton University Hospitals Trust on a new research project. The project seeks to explore the experiences (good and bad) of CUP patients, and their family members and friends during diagnosis and treatment. Very little has been published about peoples' experiences of living with CUP or best practice in caring for, or supporting, them. By adding to existing knowledge, this study has the potential to inform the development of future care for CUP patients. If you would like to help with the study, please contact the study researcher, Dr Rebecca Foster, at the U Tel: 023 80597581 Helping with the research would involve taking part in a telephone interview, or face to face interview if you live close to Southampton. The interview will be up to one hour long and will be held at a time convenient to you. Those who wish to may also be invited to take part in a focus group discussion.

Treatment of CUP in UK *Posted on: December 1st, 2011 by Peter MAC*

Is ECX the primary chemotherapy for treatment of CUP in the UK in cases where diagnosis can't identify the location or type of primary? Has work been done on identifying the success rates of this particular chemo or finding alternatives or is that part of the purpose of the CUP One trials? Peter

Peter – there is no consensus on treatment standards for CUP – this won't surprise you. The patients pathological features (supplemented by the molecular profile of the tumour, e.g the Lab21 test, for those that go that route) will point the oncologist at the type of chemo regimen that is likley to have the optimum effect. ECF combination is often used because it has a broad spectrum activity against a variety of known cancers. ECX is thought to be comparable but with greater tolerability and fewer complications. The trial is, in part, to assess its efficiency. ECX has been used in CUP for a long time and the trial has some interesting research objectives linked to improved diagnostics. The trial protocol will limit who can and cannot be put on the trial in relation to their diagnosis. Prognostic predictors are weighed-up in clinical decision making to achieve the greatest benefit, whilst avoiding unnecessary toxicity. In short, no one would be put on the trial if the ECX regimen wasn't thought the most appropriate. This is getting a bit complex – ask me questions if unclear but remember I'm a layman! *John (Moderator)* says on December 1, 2011 at 11:29 am

I do not know what ECX is. I was treated with Taxol, carboplatin and etoposide. My initial tomour was found in an inguinal lymph node. That was in September 2007. I started the chemo in December 2007 & continued until April 2008 (6 treatment sessions). Today I am still cancer free. Dianne *Arcticnurse* says on December 1, 2011 at 7:18 pm

Sorry – I should have explained. ECX is this combination: epirubicin, cisplatin, capecitabine. Details of each drug can be seen on the Macmillan website here (but I know and understand that some people would really rather not know the details): <http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Chemotherapy/Individualdrugs/Individualdrugs.aspx> *John (Moderator)* says on December 2, 2011 at 9:58 am

Thanks John and Dianne. Increasingly it seems that the most appropriate route is to find ways of more closely identifying the type of cancer primary so that the chemo can be as targetted as possible. Molecular/genetic type testing such as Lab 21 seems one very relevant way forward. Are there any NHs clinical trials planned or does this form part of CUP One trials. ECX (and I guess ECF) seems quite a broad brush approach introduced when the pathology results can't give any indication of the primary. I have been told that the success rate for ECX on CUP is variable. Is there any data on this? Peter *Peter MAC* says on December 3, 2011 at 10:39 pm

Gene expression profiling is part of CUP-One. ECX, ECF is broad brush, for the reasons you give although the histo-pathology is giving sufficient pointers that makes it an appropriate treatment. I can't immediately point at any data but I think 'variable' is probably correct. Sadly, it is not possible to be targeted with CUP treatment until it is better understood. *John (Moderator)* says on December 5, 2011 at 10:34 am

Thanks John Being based in Wales we can't participate in the CUP One trials as its only in England and parts of Scotland. My wife is on EXC and we are having a Lab 21 test carried out. Is there any contact we could make with the team /lead for the trials to identify info on the gene profiling that is part of the test and if relevant we could ask our Oncologist if we could participate? Thanks Peter *Peter MAC* says on December 6, 2011 at 10:29 am

I hadn't realised Wales was excluded (it is exasperating that there are so many national distinctions in the NHS). Your wife won't be allowed onto the translational part of the trial without the clinical part. Anyway, you will be getting much the same info by going the Lab21 route. I fully understand the wish to try every avenue and you can try ringing the trials office – see detail on link below. I think the only way round would be to be treated by a clinician across the border in a unit that is signed-up for the trials. I think the Christie in Manchester has just come on stream.

http://www.cupfoundjo.org/research_and_resources/trials.html *John (Moderator)* says on December 6, 2011

Radiofrequency Ablation *Posted on: November 21st, 2011 by Peter MAC*

Hi Does anyone have any knowledge or experience of Radiofrquebcy Ablation (RFA) as part of treatment for reducing secondary lesions? Peter

Hi there – I had RFA to remove a lesion on my liver in 2008, and it was a success. The process itself was very simple (required an overnight stay in the hospital but I felt well enough to go home just a few hours after). So in a nutshell, the RFA removed the lesion and was an easy procedure. Good luck. *kplondon* says on November 21, 2011 at 7:21 pm

Treatment diagnosis *Posted on: October 4th, 2011 by Peter MAC* [16 Comments](#)

The received medical opinion surrounding treatment of CUP appears to be based on the understanding that this particular form of cancer is not curable but is treatable. Why is this? Is

it because not identifying the primary there can be no guarantee that the cancer will not return even after the most precise chemotherapy? Excuse my ignorance on this.

that was my first diagnosis now im told im in remission, I think because they never find the primary they cant be sure its not lurking somewhere. To my knowing no one is ever told they are cured as there is always a risk that it can return one day. They will say with curative intent and if it hasnt come back and you die of say a heart attack you were cured of cancer. Does that make sense. [sallie](#) says on October 4, 2011 at 3:04 pm

Sallie is spot on but I'd add that: the clinical objective with a person who presents with an "uncertain" cancer is, through investigations etc, to try and get them into a "sub set" which has greater clarity for treatment. The better the handle on the genetic make-up of the initial cancer the better the chances of zapping it. (We are presently fixated about the site in the body where it originates but its genetic signature is the significant factor.) The messages that go out from the experts these days about cancer in general is to the effect that an increasing no of people will get cancer but that it should be seen as a chronic i.e. long lasting condition and because the treatment is becoming cleverer (more targeted and less systemic) the impact should be less on the patient. This is a bit glib and general and when any cancer has spread it becomes harder to treat. The rule of thumb is that if someone is clear after 5 years it is "cured" but its such a loaded word that people are reluctant to use it. [John \(Moderator\)](#) says on October 4, 2011 at 5:59 pm

Thanks John this also helps clarify things. It does seem unfortunate that the NHS does not seem to have yet picked up the use of genetic testing as provided by orgs such as Lab 21. Is there any reason why? Peter [Peter MAc](#) says on October 5, 2011 at 3:45 pm

Peter – lab21 is too new for the nhs to utilise them. They are aware of them and didn't tell me – which I was angry about! They are keeping their eyes on the results though and I'm sure they'll use them in the future. [Cheryl](#) says on October 7, 2011 at 11:35 am

The NHS will be swayed by financial arguments and the proven ability of molecular profiling. When on the NICE Guideline Development Group I fought for greater use to prove its value and it was agreed that it should be used for trials but not routinely. The average no. of investigations facing a CUP patient, in a trial a few years ago, was 19. Now if we could prove that molecular profiling reduces this to one we are on a winner. I'm working on it but it is not going to be a quick win. [John \(Moderator\)](#) says on October 8, 2011 at 5:18 pm

Thaks Cheryl and John Yes it does seem strange that NHS are slow to pick up on such things-One expects them to carry out or check clinical trials for 'new' methods- but it does seem suprising that they give relatively little, if any, consideration to seriously looking into this. John If there is anything I can do to help such as writing to our Health Minister (in Wales) asking her what consideration is being given to utilising molecular profiling?Peter [Peter MAc](#) says on October 9, 2011 at 8:37 pm

So glad Peter put me on to this site it is answering a lot of the questions I have. I have contacted Lab 21 today and am going to push our oncologist in to referring us as I

hope this will help with identifying the primary and then hopefully steer the treatment in the right direction. If they get good results it will help the case for inclusion in diagnosis on the NHS. If we had been on NHS it could have saved the cost of the ECX that has not worked for my wife but more of a concern for me is it could have saved us 3 months on drugs that did not work. 3 months is now a significant amount of time for us as we now have to wait that long again to see if the Gemcitabine works
duvlin says on November 29, 2011 at 2:32 pm

Does anyone know the costs of the Lab21 diagnostic service? I have just been diagnosed CUP and am waiting to start chemo with Xelox. Devastated and searching for any help I can find. Being given a 6-9 month prognosis focuses the mind, between weeping sessions.
philh says on March 19, 2012 at 9:57 am

The figure on this page

http://www.cupfoundjo.org/diagnosis_and_treatment/special_tests.html was right last year but it may have changed. I know others have used recently and may comment or contact them direct perhaps

<http://www.lab21.com/ClinicalLab/Services/Patients/CANCER/CancerofUnknownPrimaryCUP.aspx>
John (Moderator) says on March 20, 2012 at 8:59 am

Hi philh, Lab 21's CUP CancerTYPEID test costs £2,200.00 and requires material from a biopsy and your Oncologist requests it. The company are very helpful so ringing them up, as John suggests will be a good idea. Your Oncologist and any second opinion you seek will use the outcomes of the test along with the other evidence that they have to formulate a hypothesis. Many people have found the outcomes of the test very useful and helped point to specific cancer type and change of chemo treatment. The test outcomes seek to point to probability of cancer types. Please also explore any other potential tests with your Onc. My wife had the Lab 21 test carried out just before Xmas and the result pointed to 59% Intestinal. Both our Onc and our second opinion were not convinced so our second opinion suggested further tests on the biopsy material (which are available on the NHS). He suggested a test for KRAS Wild which (though my wife had to have a second biopsy) has produced a positive result with the resultant chemo treatment of Cetuximab. (Though we now have other problems as Cetuximab isn't accepted for this treatment here in Wales so our Onc has had to apply for special funding.) It is devastating when you are given the diagnosis but remember you must keep positive. There are many on this website who were diagnosed with CUP and are now into remission.

Keep us informed and any help I can give let me know.
Peter MAc says on March 20, 2012 at 9:44 pm

Thank you Peter. I have pointed my oncologist at the Lab21 option, but his view was that the tests they have already done at Royal Derby cover things, with Lab21 offering nothing more. The histology has narrowed down the primary to clorectal, gastric or pancreatobiliary origin, and my planned chemo with Xelox focuses on that. I have asked him to check back with his pathologist to be sure, but it look like Lab21 aren't going to help me find the silver bullet. I have requested a referral to Royal Marsden and Christie's, which Royal Derby have agreed to arrange. I'm also in dialogue with The Fred Hutchinson Centre in Seattle, and M D Anderson in Houston to see if they have any better options available to me. The conference sounds interesting. Any chance of attending?
Best, Phil philh says on March 21, 2012 at 12:04 pm

Thanks Phil it looks as if you are tackling this the right way. We delayed going for second opinion until after half way through the first chemo. Our second opinion was a lead in CUP and pointed to several possible treatment options. You are right to go for second opinion now-it can only help in the diagnosis. Either Royal Marsden or Christie are excellent -we've recently been going to the Christie. It still may be worth going for the Lab 21-our Onc indicated that he felt it wasn't yet advanced enough but I do know of people whose test outcomes have helped provide further more targeted chemo. Remember Dianne from Canada's comments on another thread in this meeting space: '... the statistics you read are other people's numbers.' Keep positive. Re the conference: John has recently posted a thread on the conference under the 'Change' category. I believe that there are vacancies. Best wishes
Peter *Peter MAC* says on March 21, 2012 at 3:26 pm

I've put an additional testing service on the website today from Caris – a company I've only recently come across.

http://www.cupfoundjo.org/diagnosis_and_treatment/special_tests.html

It is an interesting one in that it undertakes multiple approaches *John (Moderator)* says on March 28, 2012 at 10:17 am

Can anyone tell me about clinical trials or further result based testing in Australia (S.A.). My second opinion, got after first day of radiotherapy, pointed to other tests and also likely primaries not prev. mentioned. All expensive private cost. However, also said wouldn't make any difference as in lymph nodes metastases. Positive note about extending life was some relief, given how harshly I had been treated by indifferent surgeon who rejected surgery after I was told was intended, and had to wait three weeks for the real nightmare to start. Radiotherapy and chemo now to try and control. *Katherine* says on November 17, 2012 at 1:08 am

Treatment and diet *Posted on: September 20th, 2011 by John (Moderator)*

Further to recent discussions on diet and in case people haven't seen the report in the papers recently: "Omega-3 and omega-6 fatty acids in fish such as salmon, mackerel or sardines can make cancer cells insensitive to cisplatin treatment, found Dutch researchers at the University Medical Centre, Utrecht". <http://www.independent.ie/health/latest-news/fish-oil-inhibits-chemotherapy-claim-researchers-2874364.html> I've no idea how valid this finding is but some CUP patients will be on Cisplatin. I've no idea how valid this finding is but some CUP patients will be on Cisplatin.

I'm confused by the mixed messages coming out of research in this field because previous research has identified the value of Omega 3 enhancing the positive effects of Cisplatin. (Science Daily 2009: <http://www.sciencedaily.com/releases/2009/04/090401200441.htm>) *Peter MAC* says on October 1, 2011 at 2:39 pm

Interesting – well spotted Peter. I think one would need to study the respective reports very carefully to make a judgement on their science. These seem a bit like so many of these health studies where one report is contradicted by another (and the headlines or summary can mis-represent the true picture). I think if a patient undergoing treatment is concerned it should be a question for the treating physician (although I've never found any particularly interested in understanding diet, yet it is a vital topic for the

patient). I have found the Penny Brohn Cancer Care (the new name for Bristol Cancer Help Centre) good on diet etc. <http://www.pennybrohncancercare.org/> *John (Moderator)* says on October 2, 2011 at 2:34 pm

ECX-chemotherapy *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 everyone has different responses to ECX so it is really important not to generalise. The one thing I must say is don't assume because the daily tablets are in oral form that they are somehow weaker than the IV medication. Sometimes they have the more profound side effects. Each day of chemo is a day nearer to clearing your system of the cancer cells. Gillian *gillianb* says on September 13, 2011 at 6:31 am

Hi Gillian Thanks for replying, I was hoping that the tablets would be weaker but the more I've read the more I learn some of the side effects are worse. The most common effecting the feet & hands with blisters, will have to invest in lots of aqueous cream. I have to be positive as you say every day of chemo is one step closer to clearing our body of cancer cells. Anne x *willow* says on September 13, 2011 at 8:03 pm

Hi Anne As you know Mel starting tomorrow (Tuesday) and we've been told-drink lots of liquids and told like yourself to use aqueous cream. You've probably seen the Macmillan page: <http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Treatmenttypes.aspx>

Also been told by someone who had carboplatine that not eating too fatty a diet helped her. Also told by Sallie from this site and a friend that had three courses of chemo that keeping positive each day (as difficult as that can be) and keeping motivated each day by setting things to do helped a lot. As you say every day of chemo is one step closer to clearing the cancer cells Best wishes again and we'll keep in touch Peter *Peter MAc* says on September 19, 2011 at 6:26 pm

My wife had terrible trouble with her feet on the ECX treatment to the extent that she could not walk. Tried a couple of the creams but was then recommended Udder Cream (sounds silly) and this was brilliant. My wife got this via the internet and it was not expensive but really did work. Her hands were not so bad but it helped with those to. Worth trying if your other creams do not work. *duvlin* says on November 29, 2011 at 2:37 pm

Gillian, you are right. It is very important to know and keep asking questions. It's unreal the contradictions you may find in the medical profession. Like you, I went from being told almost nothing, despite saying I wanted to know, to getting after 3wks wait for surgeon supposed to operate told the very worst. No op. no cure, limited time to live. Blunt, cold, hit like a sledgehammer despite my Internet research. Since, have found contradictory info a little more positive. You do, and should do, your own follow up and do not be put off! Only you have the best interests invested in yourself. I use Sorbolene to date no problems, am in very early treatment days so yet to see how much side effects, don't like what I read given my known sensitivities re skin reactions and swelling. Last already a BIG problem, frightened of losing my mobility as had successful, each leg , knee replacements last two years now compromised. *Katherine* says on November 17, 2012 at 12:44 am