

Occult Biofilm Bladder Infection/Embedded Biofilm Bladder infection

An introduction to the group with frequently asked questions.

We believe Interstitial Cystitis is an Occult or Embedded Biofilm/intracellular Bladder Infection (OBBI or EBBI – there is no difference) and that patients are currently being misdiagnosed with 'Interstitial Cystitis' because these infections cannot be picked up using standard testing methods which have not been revised for over 60 years. Mismanagement of symptoms with inappropriate antibiotic prescription, can lead to the formation of biofilm or embedded intracellular infections. Instead of believing that the bladder can become inflamed for no apparent reason with no hope of a cure (as is the case with IC), we believe that there is solid scientific evidence that we have hard-to-detect, low level, occult/embedded biofilm intracellular bladder wall infections. We have numerous articles from research studies located in our obbinfo.com webpage for you to read and share with your GP.

If these articles are not enough to convince you of this viewpoint we also have many success stories within the group and many wonderfully supportive group members who will be happy to share them and guide you through your journey to regaining your health! All this information can be found on the OBBINFO.com website under OBBI General Topics – Success stories.

Frequently Asked Questions

What is the difference between 'Interstitial Cystitis' and an 'Occult/Embedded Biofilm Bladder Infection'?

We believe that there is absolutely no difference between the two, because Interstitial Cystitis IS an Occult/Embedded Biofilm Bladder Infection. We believe that OBBIs/EBBIs are being misdiagnosed and that there is a cure to the pain and symptoms that so many are suffering with what is widely referred to as IC.

What is an occult/embedded biofilm bladder infection (OBBI/EBBI) and how does it develop?

An Occult/Embedded Biofilm Bladder Infection (OBBI/EBBI) is a bladder infection that is not apparent or detectable through current standard clinical methods alone. This is usually because the infection will have formed a biofilm and is therefore "Occult" or Hidden and embedded within the bladder wall with the bacteria colonizing the cells of the bladder wall (often referred to as an intracellular biofilm infection). The two links below will provide a more detailed explanation to help you:

<http://obbinfo.com/a-picture-guide-to-the-evolution-of-a-chronic-uti/>

<http://obbinfo.com/wp-content/uploads/2016/03/IMperial-college-Women-with-LUTS-bladder-biopsy-specimens-cultured.pdf>

What is a biofilm?

A huge number of the pathogens we harbour in our bodies are grouped into communities called biofilms. In an article titled "Bacterial Biofilms: A Common Cause of Persistent Infections," JW Costerton at the Center for Biofilm Engineering in Montana defines a bacterial biofilm as "a structured community of bacterial cells enclosed in a self-produced polymeric matrix and adherent to an inert or living surface." Put simply this means that bacteria can join on essentially any surface and start to form a protective substance around their group. This protective layer is made of polymers – substances composed of molecules with repeating structural units that are connected by chemical bonds.

Biofilms make it extremely difficult for standard testing methods to initially detect the infection and then, when the infection is detected it is extremely hard for the antibiotics to penetrate the biofilm and eradicate the bacteria. The bacteria within these biofilms are also able to communicate with each other and as each has different resistance, they can teach each other to become more and more resistant to antibiotics.

More on biofilms:

http://www.hypertextbookshop.com/biofilmbook/v005/r001/Contents/01_Topics/01_Chapter_1/02_Section_2/01_Beginner/01_Page_1.html

http://www.youtube.com/watch?v=M_DWNFFgHbE

<http://www.icsuccessonline.com/Martha.htm>

When and why do Biofilms form?

Biofilms form when bacteria stick to surfaces in aqueous environments (such as the bladder) and begin to excrete a slimy, glue-like substance that can anchor them to all kinds of materials – such as metals, plastics, soil particles, medical implant materials and, most significantly, human or animal tissue. Why? Because in doing so they can combat the cells of our immune system that are attempting to destroy them and the antibiotics we take to help it.

Is there a single causal bacterium?

No, biofilms/intracellular infections are polymicrobial (i.e. made up of more than one bacteria) in nature and although one bacterium may help to create the embedded infection, the different bacteria communicate and develop biofilm/intracellular communities. Standard urinary testing for infection is based on looking for one single causal bacterium such as e coli and multiple bacteria are dismissed as mixed growth. This misdiagnosis can lead to untreated infections with the potential to set up biofilm intracellular infections if the symptomatic bacteria are not diagnosed and treated correctly.

<http://obbinfo.com/wp-content/uploads/2016/03/BiofilmsUTIs2014.pdf>

But surely the urinary tract is sterile?

No, this is a common misapprehension. The bladder regardless of infection has been found to have over 500 different strains of bacteria within it and many of these bacteria currently identified can form biofilm colonies. The paper and story linked below provides more information

<http://obbinfo.com/wp-content/uploads/2016/03/Urine-is-Not-Sterile-Use-of-Enhanced-Urine-Culture-Techniques-to-Detect-Resident-Bacterial-Flora-in-the-Adult-Female-Bladder.pdf>

<http://www.livescience.com/45800-confirmed-urine-not-sterile.html>

Why does my GP not know what an OBBI/EBBI is?

Chances are, your GP will not know what this is because medical training teaches them to look for a single causal bacterium from urine testing results. If the sample is negative or is shown to have more than one bacterium then it is felt that infection is not evident or contaminated and you receive the diagnosis of Mixed Growth, Low Growth or Insignificant Growth. Treatment if a sample is positive is for an acute infection with those suffering from recurrent and then chronic infections needing specialist referral onto a Urologist or urogynaecologist. Biofilm and Embedded Intracellular infections are slowly becoming more widely known as research becomes available but there is a desperate lack of information from the Government and National Medical Authorities as to how to diagnose and treat not only recurrent but chronic embedded infections. If you're lucky and your Urologist or GP is open to treating you for an OBBI/EBBI (which in our experience the majority won't be preferring to follow IC or Pelvic Pain guidelines), then you can take documents from OBBINFO.com into your practitioner to support your findings.

Professor James Malone Lee has written the paper "The Treatment of Lower Urinary Tract Symptoms" specifically for GPs, Physicians and patients. Please use this as a starting point when seeking a referral to one of the specialists listed at the end of this document. This paper can be found on OBBINFO.COM under Professor Malone-Lee Research papers.

How is a biofilm/intracellular infection detected?

There are very few doctors who are able or indeed know about specialist culturing and the current standard testing used by GPs, Physicians and specialists globally are missing up to 50% of infections which has led to the development of these embedded infections. In one study published in 2017, it was noted that E-coli UTI infections were missed in one fifth of a patient cohort using more detailed urine analysis – this study can be found in OBBINFO.com under OBBI Research Papers. The specialists mentioned at the back of these notes test using more detailed non-standard protocol methods as they have found the current testing simply inadequate. These tests can include a longer culture time, different urine microscopy and/or the analysis of blood samples (for those in treatment with Ruth Kriz).

Where can I get a specialist culture?

Information and contact details for the specialist doctors that patients in the Group are using to treat their infections is located at the end of this document. We hope to build on this soon but if you are not in these areas, please do not worry. You can send your sample to the testing facility in the US (United Medical Labs) via Fedex, and then use this information with your own practitioner. Please note that Prof ML is no longer offering a sediment culture to all patients preferring to treat on urine microscopy and symptoms. This will continue until new more advanced testing comes online in the next few years.

What do I need to do before having a culture?

If testing with Dr A or using United Medical Labs (both use Broth Cultures), please ensure you stop all medications/supplements for your bladder for at least 7 days. For those using D Mannose or other natural herbal supplements to treat their infections, these must be stopped 48 hours before testing. Anyone taking Azithromycin must stop 10 days before testing.

The reasons behind these timings is due to the life of the antibiotic or supplement you are taking and how long it resides in your body which will affect test results. Always contact Dr A's office or United Medical labs to discuss your medications in advance of testing including any medications for other conditions that do not affect your bladder i.e. thyroid, bowel etc. They will be able to advise you as to what can be continued and what needs to be stopped and the relevant time-period for cessation.

In all cases, Azo Standard should be stopped 24 hours before your sample as it states on the packaging urine samples will be affected by this medication.

United Medical and Dr A's office will provide you with full instructions as to how to collect your sample, the packaging required and how to mail it.

Try to provide an early morning sample where possible as it will more concentrated. If this is not possible, limit your fluids for around 3 hours before your sample so the sample isn't too dilute. Be aware that the very nature of a biofilm/embedded infection means that the bacteria can flux in and out of the bladder wall under the right conditions hourly and daily and it is therefore recommended that any testing is carried out when you are experiencing strong symptoms or a "flare". That way you have a greater chance of identifying some of the bacteria embedded into the biofilm and bladder wall that have come out during this flare.

How are biofilm/intracellular infections treated?

Currently the treatment for these infections is long term, high dose antibiotics that are specifically prescribed based on the results of your culture or urine microscopy and symptoms. If you are unable to take antibiotics for any reason, there are alternatives using natural methods or anti-bacterials. These can be discussed with one of the specialist doctors and tailored to your individual needs. There is no one antibiotic that cures all and often it can take time to find the right combination of antibiotics to successfully reduce symptoms and the infection. The length of treatment will vary between person to person based on how long they have had an infection and the bugs have been lying dormant in your system thus enabling a biofilm/intracellular infection to establish. For some, it may only take a few weeks, for others, up to two years or longer. Please note that at present it cannot be guaranteed this is necessarily a total cure given the nature of these infections particularly for those who have had infections over many months and years but people are getting well in treatment and getting their lives back after previous treatments that haven't helped or have made things worse. As with any infection, symptoms may return but you will have the knowledge and doctor's support to prevent any future infection being left untreated and developing into another OBBI/EBBI.

Remember your infection is individual to you, the length of time it takes to heal is down to you. Don't compare yourself to others in the group who are getting better. Their bugs are different, their bodies are different and their healing time will be different. Work on your healing and yours alone. We cannot stress this enough.

How have I ended up with an OBBI/EBBI?

There are many causes from which a person can contract an OBBI/EBBI. This will vary from person to person and it is important that you find out why this has happened to you. Think back to when it began and question what happened. There will always be a reason. Some of these can include:

- History of UTI's not fully or correctly diagnosed and treated
- Misshapen bladder
- Bladder surgery causing ongoing infection issues
- Possibility of vaginal/bowel prolapse
- After being catheterized/cystoscopy/pelvic surgery including mesh implant/urethral stretch
- Menopause/Peri-Menopause
- After a new sexual partner
- Being on the birth control pill or using the Mirena Coil (*if you are please find an alternative as this can cause symptoms!*)
- Low immune system caused by auto-immune issues, Lyme disease, low thyroid, a strong viral infection or CFS

Two elements worth mentioning in more detail are thyroid problems and hormone problems. Many of the group members treating their OBBI/EBBIs have discovered problems with their thyroid and hormone levels. This has proved to be a vital piece of the puzzle for them and both can be significantly linked to the pain you are feeling, due to the immune system being slightly compromised. Further information is found on later pages in this FAQs doc.

Will food affect me if I have an occult/embedded infection?

The simple answer to this question is yes, food may affect you. For many people diagnosed with IC, diets they are usually always advised to follow post diagnosis offer them some relief. This is because they are no longer irritating their inflamed and infected bladders with sugary, acidic or spicy foods, which in turn increases pain and allows bacteria to flourish by feeding on the sugars or carbohydrates.

There are many different diets that could be followed, the choice of which is completely up to the individual. Becoming gluten, sugar or dairy free appears to help some individuals. As a starting point the food list linked below may help. Your bladder will guide you as to what are triggers for you and what are not

<http://www.ic-network.com/patient-resources/diet/diet-introduction/>

There has also been a lot of success within the group using anti-candida diets, alkaline, or low histamine diets. If you are unsure, stick to a completely safe 'elimination' diet of lamb or white fish, brown rice, rice cakes, boiled water and fresh vegetables. Always drink lots and lots of water, filtered, bottled or boiled if possible as tap water contains irritants to the bladder. Lots of people find that warm or tepid water is better than ice cold water.

The OBBINFO.com webpage has more information about diet and some helpful links in the OBBI General Topics section. As with anything detailed in this document response to trigger foods and drink is very individual and you may have no issues at all but we include this information as some of our specialists have advised caution when early in treatment, alongside the views of those who are members of the OBBI FB groups and have noted their own triggers plus known information made available at conferences and in research listing bladder irritants. You can always reintroduce once the bladder starts to heal and the inflammation reduces. This information is not prescriptive, you know your own body and what, if any, issues you may have.

How much fluid should I drink?

This is very individual and some find that by drinking 1.5-2 litres of water a day things are kept flushed and acidic urine kept to a minimum. Others can drink less and are ok as their bladders are stronger and less inflamed. The rule of thumb as advised by one of our specialists is that your urine should look the colour of a pale white wine – any darker or more yellow and you are not drinking enough and can run the risk of dehydration. Over-drinking is not advised as this will flush out the antibiotics and certainly when you take your abs, try to restrict fluids for an hour to allow them to get into your system.

Do not drink carbonated/fizzy water as this contains carbonic acid which is a bladder irritant. Additionally, tea or coffee are dehydrating and contain caffeine, a bladder irritant. Until your bladder feels less inflamed its best to avoid during early days of treatment. However, we should advise this is individual to each person. Some can carry on drinking tea, coffee and fizzy drinks throughout their infection treatment with no side effects.

It is recommended you should always keep yourself hydrated regardless of whether you are ill or not. If you are thirsty then drink. Remember when you are in a hot or humid climate you will dehydrate more so always keep a bottle of water close and keep your fluid levels topped up. Alcohol does not replace water and can often cause a horrible holiday flare. Fruit juices will contain sugar and this will feed your bugs who thrive on sugar and will also irritate the bladder so avoid or keep to a minimum when early in treatment.

Should I still have sex?

For those of you lucky enough to be able to have sex and are wondering if this is a good idea, unfortunately we must tell you that it is *not* when early in treatment. The act of penetration alone will most likely increase pain purely because the vagina is so close to your inflamed urethra and bladder and penetration irritates these areas. Try to give the bladder time to heal with the treatment regime before you attempt sex and only do so when you feel comfortable and well enough. Do not feel pressured into this. You must be honest with any partner and they should have respect for you when you are healing and in treatment.

Having sex is likely to add to the bacteria already inside your bladder as more bacteria may get pushed up through the urethra when having sex. There is also a theory that having sex breaks up the biofilm/embedded infection by agitating the bladder wall, therefore releasing planktonic bacteria into the bladder, and increasing pain. This is also applicable to orgasm whether through penetrative sex, outercourse or masturbation.

If you still wish to have sex having read the above, then we suggest that you bottle wash both before and after sex, get your partner to thoroughly clean themselves and scrub fingers before sex and use plenty of a non-irritating water based lubricant such as Yes or Sylk.

<http://www.yesyeyes.org/index.htm>

Drink a pint of water before sex and then urinate immediately afterwards and drink plenty of water. Make sure you keep up your antibiotic regime even if things have completely settled. Even some of our success stories are still reporting flares after sex and have found they have had to take antibiotics afterwards for a few days.

What else should I avoid when starting treatment?

As with anything detailed in this document response to the items listed below is very individual and you may have no issues at all but we include this information as some of our specialists have advised caution when early in treatment, alongside the views of those who are members of the OBBI FB groups and have noted their own triggers plus known information made available at conferences and in research listing bladder/urethral irritants. None of this is prescriptive. You can always reintroduce once the bladder starts to heal.

- Baths (a dirty bath will harbour bugs)
- Swimming pools (the chlorine can irritate your urethra and bladder and will again breed bugs)
- Hot tubs/Jacuzzis (they are a breeding ground for bugs)
- Scented toilet paper
- Douching (will upset the natural balance of your vaginal secretions and can lead to Bacterial Vaginosis/Thrush)
- G-strings or synthetic underwear
- Tight jeans
- Scented washing powder/fabric softener
- Coffee
- Tea
- Cranberry Juice/Fruit juices (extremely acidic and full of sugar which will feed your bugs)
- Fizzy drinks (carbonic acid, a bladder irritant)

- Chocolate
- **Alcohol!**

Additionally, always wipe 'front to back' and research the Angela Kilmartin bottle washing technique for each time you pass a bowel movement or have sex. (<http://www.angelakilmartin.com/cystitis/>) as bacteria can be transferred from the anus to the vaginal/urethral entrance causing UTIs.

Help! I'm having a flare! What can I do?

We all know how terrible it is to go through a 'flare'. This can be common when not on medication, having had sex, eaten or drunk a trigger food or alcohol, the bladder lining naturally shedding or when taking antibiotics early in treatment due to the nature of the infection. When you irritate the bladder, a new type of bacteria from within the biofilm/intracellular infection will then seep out and cause pain and become active or planktonic in your bladder. Additionally, bacteria release toxins into the bladder causing more pain.

In many ways try to look at this as a good thing as it means your infection is being broken down either through the release of bacteria into the bladder or by the natural shed of the bladder wall every few months but you should always consult your specialist doctor when this happens and ensure you have antibiotic support to mop up the bugs that will be in your bladder preventing them from creating further biofilm/intracellular colonies.

These relapses are common and you must always remember it will pass. Patients always come out the other side. In the meantime, try to relax, take lots of deep breaths to avoid stress and drink lots of water. A teaspoon of baking soda in a glass of water can relieve pain by reducing the acidity of your urine. Azo Standard can help (this can be purchased online if you are not in the USA) and an ice pack will numb and distract the nerves causing your pain and provide relief.

We would recommend avoiding heat pads or a hot water bottle between the legs as these provide your OBBI/EBBI bacteria with a perfect place to breed and will also encourage thrush. An antihistamine can prevent the histamine release that mast cells generate through stress from causing further pain in the bladder and additionally cut off the food source that is histamine for bacteria and thus prevent active bacteria from multiplying in the bladder. Remember your bladder has the highest level of nerve endings of any organ in the body which is why we feel this pain so badly.

The OBBINFO.com webpage has more information about managing flares and these are found in the Grabsheets and Factsheets sections.

OK, I've started treatment but I feel worse or no different after a few weeks/months

We can only say that it's a question of managing expectations. Lots of people jump into treatment and expect that after a week or so things will suddenly get better and then struggle to understand why the pain is sometimes worse or no different. It's often down to several things:

1. Your bugs and symptoms - whilst the bugs identified may be susceptible to the ab prescribed and be knocked back often another bug occupies the space vacated and you may need another ab or add in naturals such as Oil of Oregano, Grapefruit Seed Extract, D Mannose (if E. coli present or suspected). Symptoms can change depending on the bacteria.
2. How long you have had symptoms. An embedded infection is just that, embedded into the bladder wall so will take time for the cells to shed or release and come to the surface of the bladder wall and become active in the bladder where the antibiotics can target them.
3. Other contributing factors such as hormones, thyroid, Lyme disease, gut health or other illnesses which will weaken your immune system. Some of these you will have to explore and treat to add a piece to your jigsaw.
4. Pelvic floor issues causing additional regional pain (see section in these notes about pelvic floor therapy).
5. Any ab resistances you may have. Bugs are unbelievably adaptive at resisting and mutating.
- 6 The inflammatory effects of infection in the bladder and body can often take a lot longer to resolve than the infection and these symptoms will take time to resolve.

Dogged persistence is the name of the game here and for some it can take weeks, for others months and for some years. Remember even if you are only seeing 5% improvement each day it's still improvement and whatever you do, don't compare yourself to others on here. That way leads to a downward spiral of negativity. Your bugs, your body, your rules. Focus on your healing and yours alone.

You must give this a good shot and take the good days and bad. If things haven't improved then decide what you want to do and talk to your specialist but please try to be patient at first. This is not a quick one week fix. Always keep your specialist informed about your progress. If things worsen significantly or you get a reaction to medication etc. e-mail them immediately. Medications can be changed.

If you suffer breathing issues or a tight chest, your temperature increases, you become dizzy or faint, develop a rash or heart palpitations, stop your medication and get to A&E or the Emergency room. Take all medications and your most recent treatment letter from your specialist with you.

My symptoms have increased. Can I have a UTI on top of my OBBI/EBBI?

The answer to this is **no**. You **cannot** develop a UTI on top of your OBBI/EBBI. You already have a UTI, it is not possible to have two. It is most likely that the bacteria within your bladder have somehow increased, whether that be due to sex, irritation from food or bladder wall cells have been shed releasing active (planktonic) bacteria into the bladder etc. and have antagonised the nerve endings in your bladder setting off a flare. It is also likely that the antibiotics have knocked back one bug, allowing another to take its place that may not be responsive to the current medication. Please ensure you do not take short-term medication for a UTI as this can cause resistance problems. All your bacteria are part of one biofilm/intracellular infection and it must be treated as one to be successful.

If symptoms have worsened, you must notify your specialist immediately so that they either increase the dosage or change your medication. Use the Flare management techniques outlined in this document until you receive a response from your specialist.

What is the recovery pathway likely to be?

The recovery pathway (a progression of the disease) is classically through a series of horrible flares which come and go. We all go through this. When you are in treatment, each successive flare is progressively milder and you may notice over months you will drop a symptom each time you flare (maybe there will be less pain and the flow will be better but the urgency and frequency will stay and then they will slowly go and the last symptom may be, say, burning, or itching inside the urethra). If you weren't being treated the same ups and downs would be experienced, but maybe each time you flare it will feel worse and worse as it progresses rather than slowly better. It is thought that the reason it comes and goes with "break through flares" is because the bacteria get released when the bladder changes its lining and "spits them out" from inside the bladder wall cells. This can be a natural shedding which the bladder wall does as well as provoking the bladder lining through sex, exercise or eating inflammatory foods. The bacteria are released into the bladder becoming planktonic (active) and the immune system goes on alert and causes all the symptoms. Also, the bacteria release toxins as they die causing more inflammation. More pain = bacteria crying.

Alternative treatments to Antibiotics:

Please note other than Oil of Oregano, natural medications should be taken at least 2 hours apart from antibiotics

Always check with your GP or Pharmacist for contra-indications against any existing medications you are taking (bladder or non-bladder related) before starting natural alternatives

D Mannose

For those suffering with Gram Negative bugs (E coli, Proteus, Klebsiella and Pseudomonas), D Mannose has proved to be helpful in controlling a flare or preventing an attack from worsening or for post coital UTIs.

It works by clinging to the fingers of gram negative bugs, preventing them from attaching to the walls of the bladder and urethra. When you urinate, it helps to flush out the bugs from your system. Although it is a sugar, very little gets into the body and most is excreted through the kidneys and urine.

For more information, see the attached link.

<http://articles.mercola.com/sites/articles/archive/2014/04/28/d-mannose-uti-prevention.aspx>

Take a heaped teaspoon in water 4 times a day. Build up to 8 times a day when your bladder flares or every 2 hours including at night during an acute flare for 48 hours. The key is to make sure you have d-mannose in the bladder during the course of the day and night so that the e-coli or gram negative bacteria is continually being flushed through.

You need to take the DM away from any acidic food or drink as it will counteract its effects and you need to keep your urine alkaline. Stools may be loose for a few days when first taking it.

The powder is recommended above the capsules if you can tolerate it.

<http://www.nowfoods.com/D-Mannose-Powder-3oz.htm>

<https://www.sweet-cures.com>

The OBBINFO.com webpage has more information about D Mannose and some helpful links in the OBBI General Topics section under supplements.

Grapefruit Seed Extract

Grapefruit seed extract (GSE) is truly a broad-spectrum natural antibiotic, capable of killing a wide variety of pathogens. Highly active against protozoa, bacteria, yeast and some viruses, it has been used for quite some time in the treatment of parasitic infections. It is nontoxic, generally hypoallergenic and can be administered for up to several months, which may be required to eliminate stubborn infections.

Be aware that it can interfere with certain medications and if you are on blood thinning drugs you should not take anything containing Grapefruit.

People using GSE should be aware that they may have, or may develop an allergy to this preparation. Persons with a known citrus allergy are at higher risk. Should you develop a rash or experience any other symptoms while using it, discontinue use immediately. As with antibiotics you should also take a good probiotic at the same time as the GSE will kill off the good microbiome in the gut so you need to repopulate.

Grapefruit Seed Extract – take 2 twice a day or 4-6 daily drops in water.

http://biovea.net/uk/results.aspx?AG=Grapefruit%20Seed%20Extract&TI=G-Grapefruit-Seed-Extract&c=n&gclid=CK_RuoLQg78CFSbmwgodCjcADw

The OBBINFO.com webpage has more information about GSE and some helpful links in the OBBI General Topics section under Supplements.

Oil of Oregano

Bacteria have one thing in common. They secrete a protein called urease. Scientists don't completely know the exact mechanism. But, essentially, the urease that these bacteria make allows them to adhere to the epithelial cells. These are the cells lining the urinary tract. Without this ability to adhere to tissue, these bacteria would flush out of the kidneys and bladder every time we urinated. So, if it were possible to block the way these bacteria were making urease, they would never be able to maintain an infection. And that's where the oil of oregano comes in. Oregano contains active biological substances called phenols. These phenol compounds can stop bacteria from producing urease. Many other herbs, such as cranberries and urva ursi also contain phenols but studies have shown that oregano has some of the strongest urease-inhibiting phenols.

Oil of Oregano – take 2 twice a day or twice daily under the tongue.

<http://www.amazon.co.uk/OREGANOL-P73-Super-Strength-30ml/dp/B0014AUJVE>

For those who can't tolerate the taste of the drops, then there are capsules available:

https://www.amazon.co.uk/s/?ie=UTF8&keywords=oregano+oil+solgar&tag=googhydr-21&index=aps&hvadid=185305358857&hvpos=1t2&hvnetw=g&hvrand=5990602958482340219&hvpone=&hvptwo=&hvqmt=b&hvdev=c&hvdvcmdl=&hvlocint=&hvlocphy=1006886&hvtargid=kwd-53284755484&ref=pd_sl_8pqyvx5nso_b

The OBBINFO.com webpage has more information about Oil of Oregano and some helpful links in the OBBI General Topics section under Supplements.

Urva Ursi

Urva Ursi contains chemicals, primarily hydroquinone and hydroquinone derivatives, that make it potentially useful for urinary conditions and is used to treat infections such as cystitis, urethritis and nephritis. The hydroquinone derivative, arbutin, is the chief active compound in urva ursi. It is absorbed in the stomach and converted into a substance with antimicrobial, astringent, and disinfectant properties. During urination, as it passes out of the body it acts on the mucus membranes of the urinary tract to soothe irritation, reduce inflammation, and fight infection.

However, it is a very powerful herb and it is not recommended that it be taken for longer than a month at a time and no more than 5 times a year.

<http://www.herbwisdom.com/herb-uva-ursi.html>

The OBBINFO.com webpage has more information about Urva Ursi and some helpful links in the OBBI General Topics section under Supplements.

What is Colloidal silver and where can I get it?

Colloidal and Nano silver consists of silver atoms suspended in distilled ion-less water. The particles of silver are small enough to penetrate on a cellular level and destroy pathogens of all types including bacteria, fungal spores, parasites and viruses. It is also thought to enhance the ability of antibiotics. Not only does silver get rid of pathogens, it helps promote rapid healing of the tissues infected or destroyed.

You can buy online using the link below for CS or you can get it from good health food shops. For NS it is available on Amazon. You need a 1 litre bottle and 25 ppm for the CS or 10 ppm for the NS. The recommended dosage is as follows:

For Colloidal Silver: start by taking 5ml twice a day morning and evening just on a spoon. Then work up to 10mls twice a day. It should only be taken for 2 weeks and then have a two week break and then repeat.

For Nano Silver: 1 teaspoon every hour, sublingual (hold for 2-3 mins)

For both treatments, please note that the gut will be sterilized so probiotics are needed to repopulate the gut with good bacteria.

Unlike magnesium and iron, Colloidal and Nano Silver do not feed biofilm. It should however be taken 2 hours away from antibiotics to be effective.

<http://www.colloidalsilveruk.com/>

<https://www.amazon.co.uk/Natural-Immunogenics-Argentyn-23-Spray/dp/B00GZRIS0Q>

https://www.amazon.co.uk/American-Biotech-Labs-Biotics-Ultimate/dp/B0013664GE/ref=sr_l1_s_it?s=drugstore&ie=UTF8&qid=1475252693&sr=1-1&keywords=Silver+Biotics

The OBBINFO.com webpage has more information about CS and NS and some helpful links in the OBBI General Topics section under Supplements.

Anti-histamines/Low histamine diets

Bacterial overgrowth can cause a rise in histamine released from the mast cells in your bladder. Therefore, it is important any suspected urinary tract infection is treated. The inflammation caused by histamine release can also disrupt the lining of the bladder, allowing bacteria to spread deep into the bladder creating a biofilm/intracellular embedded infection. Additionally, the gut has a high number of mast cells so it is important to maintain good gut health to prevent histamine overgrowth which can affect the bladder.

The bladder has the highest number of nerve endings of any organ in the body. When distressed, scared or upset, your body produces histamine from the mast cells found throughout the body and particularly in the bladder. Consequently, we often get that need to urinate sensation because the bladder's nerve endings have been flooded by histamine in the bladder and are now signaling you need to go (and this applies for people with perfectly healthy bladders). By taking an antihistamine you will reduce this histamine release and dial down the pain receptors that the nerve endings additionally produce (H1 and H2). Most importantly histamine is food to bacteria so by starving this food source, you prevent any active (planktonic) bacteria in your bladder from feeding and multiplying and possibly setting up new biofilm/intracellular colonies.

You can purchase Cetirizine and Ranitidine over the counter and these are commonly sold as allergy/antihistamine tablets. Atarax is a stronger anti-histamine but available on prescription only along with others such as Famotidine or Fexofenadine. Those in treatment with Vik Khullar (see details at the end of this FAQs doc) will be familiar with his treatment for Mast Cell issues within the bladder and chronic infection. There is a blood test to check for Histamine/Mast cells which measures the levels of DAO and Serum Tryptase as well as a 24-hour urine collection measure test. Additionally, any bladder biopsies will also show mast cell levels within the bladder wall.

Some people are finding that a low histamine diet is also helping their bladder as many foods are high in histamine or can liberate histamine stored in the body which the body cannot break down. To help in the early days of treatment, you could look at a low histamine diet to see if it helps with symptoms. If so, stick with it but be warned, it is very restrictive.

<http://www.histamineintolerance.org.uk/about/the-food-diary/the-food-list/>

OBBINFO.com has more information about Histamine and the Bladder in the OBBI General Topics area.

What are 'Biofilm busters'?

Biofilm busters are super nutrients that help dissolve the sticky biofilm of bacteria within the bladder. There are many suggestions as to what these nutrients are and you and your specialist doctor must decide which one(s) are best for you. Biofilm busters commonly mentioned in the group include

Interfase Plus

<http://www.functionalnutritionalsupplements.co.uk/klaire-labs>

Boluoke

<https://www.researchednutritionals.com/store/item.cfm?code=CBD202>

Arginine

<http://www.solgar.co.uk/SolgarProducts/L-Arginine-500-mg-Vegetable-Capsules.htm>

Xylitol

<http://xylitol.org/healthcare-professionals/xylitol-health-info-for-professionals>

Allicin

<http://www.allicinfacts.com/about-allycin/future-of-allycin/>

When first in treatment **do not** immediately start on one of these biofilm busters. Stick with your antibiotic regime for a few months before introducing **only one** of these to start with. The temptation is to pile in enthusiastically and think “right I’m going to get rid of this biofilm”. However, we recommend that you gradually introduce one of these biofilm busters into your regime rather than all at once as it can be very heavy on your body and may cause a flare. You are potentially bursting open a OBBI/EBBI with the usage of the above and therefore pain and frequency levels may increase as bugs are released into your bladder. You will also need the right antibiotics to mop up the bugs once out of the biofilm to stop new biofilms forming. Please also remember that there is no guarantee that these biofilm busters reach the bladder given the journey through the gastrointestinal tract and the kidneys and some specialists treating patients in this group have reservations about their efficacy. Therefore, if they don’t work for you, you can’t say you haven’t been warned.

Why do people have so many contrasting opinions on which medication to take in this group?

We all have different doctors who treat “Interstitial Cystitis” as a biofilm/intracellular infection in different ways. Each doctor has their own unique style of treatment based on what they have learnt about the condition. If your treatment is treating an infection, we have seen that ‘Interstitial Cystitis’ patients are getting well again.

My GP/Specialist has urged me to have a cystoscopy/urethral/bladder dilation –should I have one?

In short no. Unless bladder cancer is suspected or an ultrasound of your kidneys and bladder has shown up an abnormality, we would urge caution in having one. Many people have found that their symptoms started or worsened after this procedure due to more bugs being introduced into their bladders via the instruments used. Similarly, unless there is a good anatomical reason for requiring it, we would strongly urge against a urethral or bladder dilation and stretch.

Why are different antibiotics prescribed if you only have bladder symptoms or urethral symptoms?

It relates to the way the antibiotics penetrate the different parts of the urological system. That is why it is important you describe your symptoms accurately each time you see or speak with your specialist. Obviously, some suffer from both bladder and urethral symptoms so depending on which are the greater symptoms causing the most discomfort, your antibiotics will be targeted to that. Additionally, certain bacteria live in different parts of the urinary tract which can cause differing symptoms.

Should I worry about resistance issues when taking antibiotics and why are short course rotating abs so bad?

The way bacteria grow is all about survival advantage and balance. If you keep changing the antibiotic and prescribing short course antibiotics you keep changing the game, because only the bacteria that have the tools for resistance will survive in its presence and then when you change it a different set will have the advantage for that antibiotic and grow. A better tactic is a high dose persistence, because even if the bacteria is theoretically able to make an enzyme to fight the antibiotic, with persistence and high dose, that population of bacteria will eventually run out of resources and die out because fighting the antibiotic is so difficult.

Always remember that the bladder will never be sterile with zero bacteria as it has a hole connecting to the outside but at least with high dose abs the bad population will have been killed off that caused flares. It’s a waiting game and a proper war and you must have dogged persistence to wait for the bacteria to give up.

Why it is preferred that treatment is at home rather than being in hospital

It’s down to the home environment and bacterial mix. It is preferred that treatment is carried out at home rather than in hospital due to the differing mix of bacteria found in hospital and the opportunity for new organisms to develop. Within the home situation, your body has adapted to the organisms at home and can fight any upsurge. Obviously if medical admission is necessary or surgery is required (for bladder or non-bladder related conditions) then of course hospital treatment is required but always take your specialist letter with you along with the medications you are taking to ensure continuation of high dosage antibiotic treatment.

What conventional and alternative tablets are available to help with pain, lack of sleep and discomfort?

You can purchase Cetirizine and Ranitidine these are commonly sold as allergy/antihistamine tablets and stomach acid tablets but they work on the H1 and H2 pain receptors in the bladder and reduce inflammation. Amitriptyline, Nortriptyline or Dosulepin are other options, these are low dose anti-depressants prescribed by your specialist/doctor that numb pain from the nerve endings in the bladder and can also help with those struggling to sleep. They should always be taken at night as they will make you feel drowsy. Alternatively, 5 HTP is a natural product containing serotonin and will help with mood and sleep.

Heat pads/hot water bottles can offer great relief but provide the bacteria causing your infection a fantastic environment to breed and flourish and can trigger thrush. For this reason, we advise using an ice pack between the legs, some chose to place ice on the vulva and urethral area. A heat pack or hot water bottle placed on the back or lower abdomen can bring relief.

Pain relief is very individual and one size does not fit all. Discuss options with your specialist or GP. If needs be make an appointment with a Pelvic Pain clinic for further help. We will not recommend controlled pain relief in this document as we are not medically trained. If you want recommendations, ask people to PM you off group.

Pelvic Pain clinics – UK

The UK has roughly half a dozen NHS pelvic pain clinics with multidisciplinary teams in them (pain management consultants, physios and counsellors). The country's leading centre is based at the National Hospital in Queen's Square, London. The listing of clinics is as follows (you will need to research the exact hospital location in each city):

Lothian - Edinburgh
Liverpool Women's Hospital
Bristol - North Somerset, South Glos, Glos and Wiltshire
UCLH – National Hospital, Queens Square
Tees Valley - led by Dr John Hughes
Oxford – John Radcliffe hospital

How do I cope with Thrush or BV (Bacterial Vaginosis)?

Firstly, get yourself swabbed to confirm whether it is Thrush or BV especially if you have taken a course of anti-fungals and there has been no improvement in symptoms.

Your GP, Physician or local sexual health clinic (GUM) can do this. If you can tolerate a vaginal pessary for thrush, fine but many women find their bladder symptoms worsen as the pessary can dry out the vagina and irritate the urethra. Candida spores are usually at their highest around 10 days before menstruation so track your symptoms and see if there is a correlation.

It is normally best to take a course of oral Diflucan, Itraconazole or Flucanazole for 2 – 4 weeks and change your diet, cutting out wheat and all sugars (including alcohol). Lactobacillus capsules and boric acid pessaries can help as well as Grapefruit Seed Extract or Coconut Oil. Topida Topical Spray has provided great relief to lots of ladies and is entirely natural.

<https://www.salcuraskincare.com/product/topida/>

It is important to get tested for thrush as there are different strains and the “azole” fungal treatments only work on Candida Albicans. Candida Glabrata is more commonly treated by using Nystatin.

Resistance to the “azoles” is increasing and therefore it's important if your thrush does not clear up after initial treatment to be tested to identify the correct strain of candida and what will successfully treat it. It is recommended that at the end of one month's treatment you should also have a blood test to check your liver function as oral anti-fungal medications can be very heavy on the liver. If continuing treatment longer than one month please always check with your specialist and/or GP once blood test results are back.

Bacterial Vaginosis is different to thrush in that the most common symptom is a smelly vaginal discharge without itching. It may look grayish white or yellow. A sign of bacterial vaginosis can be a "fishy" smell, which may be worse after sex. Again, diagnosis via the GP or local GUM clinic is best.

About half of women who have bacterial vaginosis do not notice any symptoms but it can cause burning in both the vagina and the urethra. It is usually treated with a 5-10-day course of Metronidazole or Flagyl. Unfortunately, it can commonly come back and it may be worth using Multi Gyn Acti Gel to prevent this.

<http://www.multi-gyn.co.uk/actigel-treatment-BV-bacterialvaginosis.html>

Whether you are diagnosed with Thrush or BV, it is worth washing all bed linen and underwear using an antibacterial laundry wash such as Dettol and wash at a minimum temperature of 60 degrees.

Please see our separate document entitled [Probiotics and Thrush](#) for more information and lots of useful advice from group members who have experienced thrush or BV. It can be found on the OBBINFO.com webpage under OBBI General Topics. There is a more detailed Factsheet about thrush in the Factsheets section as well as a simple Grabsheet in the Grabsheets area.

What are probiotics and why do I need to take them?

Probiotics are friendly bacteria that we need for good health and vitality. When taking antibiotics, the 'good' bacteria that we have living inside us are also killed as well as the 'bad' bacteria causing the symptoms. To avoid further problems such as thrush and damage to the digestive tract when taking antibiotics, it is vital that you also take a probiotic so you can limit microbial imbalance. Probiotics should be taken at least 3 hours before or after antibiotics. Good brands are VSL3, Femdophilus, Culturelle, Ultimate Women's Probiotic, Prescript Assist Gastrointestinal Support, Symprove, Syntol AMD and Ther-biotic Factor I by Klaire labs. The latter is particularly good for those with very sensitive bladders. All should be kept refrigerated. The document [Thrush and Probiotics](#) in OBBINFO.COM under OBBI General Topics is recommended for more information as it is compiled from group member recommendations as to what has helped them.

Kefir

Some group members are successfully treating any gut issues whilst in treatment on high dose abs by making their own Kefir. Kefir grains contain about 30 strains of bacteria and yeasts, making it a very rich and diverse probiotic source. Kefir is a fermented milk product (cow, goat or sheep milk) that tastes like a drinkable yogurt. It is made by adding kefir “grains” to milk or milk substitutes or water for those who are lactose intolerant or avoiding dairy.

These are not grains in the conventional sense, but cultures of yeast and lactic acid bacteria that resemble cauliflower in appearance. There are two types of grains – dairy based and water based. The water based grains do contain sugar so if you are avoiding sugar early in treatment you may want to look at the milk based grains if appropriate.

Over a period of 24 hours or so, the microorganisms in the kefir grains multiply and ferment the sugars in the milk, turning it into kefir. Then the grains are removed from the liquid, and can be used again. So basically, kefir is the drink, but kefir grains are the “starter kit” that you use to produce the drink. More information can be found at the following links and it can also be purchased ready made in most supermarkets or local grocery stores. The grains can be purchased on-line or at health food stores.

<http://www.kefir.net/what-is-kefir/>

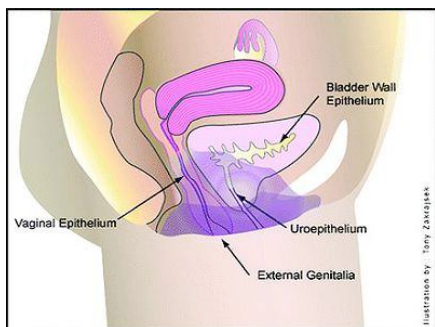
<https://authoritynutrition.com/9-health-benefits-of-kefir/>

We should add that for those with mast cell issues, fermented foods can cause histamine release so please research Kefir and its suitability before purchasing or making your own.

Why can hormones be a problem if I have an infection?

Many women will begin to suffer with an OBBI/EBBI when they become peri-menopausal or menopausal. This can cause vaginal dryness and vaginal atrophy, which in turn leads to an increase in UTI's. The hormone oestrogen (or estrogen) is needed for the vagina to maintain its natural flora and lubrication. Interestingly, the bladder also needs oestrogen and some people see a reduction in pain after adding this hormone.

The diagram below shows the areas of the urogenital tract that require Oestrogen. The darker the colour, the more oestrogen is required.



If you'd like to check if hormones are contributing to your OBBI/EBBI pain, you should ask your GP for an oestrodial blood test. They will usually offer you a Follicle Stimulating Hormone test (FSH), but insist on getting an oestrodial one as the FSH test results can come back within the 'normal' range whilst you could still have very low oestrogen levels. Ensure you ask for your results; specialists consider anything under 300 to be low. Additionally, get Progesterone and Testosterone levels checked as these too can impact on the bladder and general health. Whilst some women experience relief using oestrogen, others find relief using progesterone, although this can sometimes cause frequency.

During peri-menopause, hormone levels can swing wildly daily so blood tests should not be assumed to be the rule of thumb to determine your hormone status. Go by your symptoms such as a change in periods, vaginal/vulval dryness, vulval pain, unusual vulval or vaginal bleeding, mood swings, hot flushes, memory lapse, vaginal pain, increased levels of Thrush or BV, frequency of urination, bone and joint pain. These can indicate low hormone levels and must be mentioned to your GP or specialist when seeking advice.

Please ensure that you make the correct choices surrounding oestrogen, and oppose it with progesterone where necessary, particularly if you have not had a hysterectomy.

Additionally, check your family history, when did you mother/aunt/sister go through her menopause? Is there a history of female hormone/vaginal/urinary issues in the immediate family? Be your own detective and build a picture. Please remember that oestrogen levels in women start to decline from your mid thirties onwards so be mindful of this.

Should you choose to use this treatment, make sure you get the very best hormones and ask for bio identical where possible. To further understand bio identical hormones and their importance purchase the book 'It Must Be My Hormones' by Marion Gluck or "Screaming to be heard" by Dr Elizabeth Vliet. In these books, you will find a list of bio identical hormones that are available on prescription from your regular GP including bio identical oestrogen and progesterone.

For a detailed specialist list, Menopause Matters a search for a specialist facility. We will aim to compile a listing for the group based on personal experiences in due course. Initial recommendations include Dr Tina Peers (private clinic Surrey and Chelsea and Westminster NHS London), Dr Nick Panay (private clinic London and Chelsea and Westminster NHS), Dr Andrew Pickersgill (Manchester), Dr Julie Ayres (Leeds), Miss Anne Henderson (private clinic London) and Miss Amanda Tozer (private clinic London).

<http://www.menopausematters.co.uk/clinicfinder.php>

For those based in the US, Dr Elizabeth Vliet is a recognized hormone expert and can be consulted.

<http://www.herplace.com>

A useful website and forum group to read/join is the Menopause Matters site with further information about HRT and choices.

<http://www.menopausematters.co.uk/index.php>

For localised oestrogen treatment for the urogenital tract, Vagifem biofilm pessaries have been found to be beneficial. They are entirely topical and will treat the vagina and bladder without systemically entering the body significantly although some women still report symptoms despite the low dosage. They sit at the top of the vagina and there is no messy leak unlike other HRT treatments. Many women in this group who are peri, menopausal and post menopausal are using Vagifem and finding relief from both bladder and vaginal discomfort. Vagifem does not need to be opposed with progesterone as it is localised. However as with any HRT, please firstly discuss with your GP or specialist explaining all your symptoms and if necessary seek a blood test to identify any hormone deficiency. Family medical history and any existing medical conditions must always be considered. For example, those with Mast Cell issues may have problems with localized oestrogen as it causes an increase in mast cell production and histamine release in the vaginal and bladder tracts.

Ladies have also reported issues with the Mirena coil, a progesterone only form of birth control which is often prescribed for endometriosis or heavy periods. As this coil kills off your oestrogen and your periods, it will provide the perfect opportunity for an infection to establish due to the lack of oestrogen as outlined above.

The Depo Provera injection is also designed to stop oestrogen production. Additionally, several birth control pills are progesterone dominant. Look at your birth control method and try to see if there was a link between your bladder infection and problems starting.

Further information can be found on Hormones on the OBBINFO.com webpage under OBBI General Topics, Hormones & HRT.

Why could a thyroid problem be causing my pain?

As part of the immune system, the thyroid gland plays a crucial role in maintaining the body's defences. Hormones produced by the thyroid help regulate the metabolic rate within each cell and directly influence over 100 different cellular enzymes.

In terms of urinary infections, many cases can be linked to chronic infections of the urinary tract that were originally caused by an underactive thyroid and therefore a weakened immune system.

If you suspect thyroid issues, please see your GP for a blood test and request the following: TSH, Free T4, Reverse T3, Thyroid antibodies, B12 and Iron levels and Vitamin D levels. If your doctor is unable to offer all, please consider paying for private blood tests, which will cover these. TPA UK and Thyroid UK have excellent websites and TPA UK have rates with laboratories for blood tests at reduced rates.

For further information, the OBBINFO.com webpage has a section on Thyroid in the OBBI General Topics area with links to TPA UK and Stop the Thyroid Madness, two excellent websites with lots of information and very informative forums. TPA UK have negotiated reduced rates for Thyroid testing that you are not able to obtain through NHS thyroid testing.

<http://www.stopthethyroidmadness.com/>

<http://tpauk.com/main/discounts-on-tests-and-supplements/>

Physical Therapy or Pelvic Floor Therapy

Sadly, bladder issues can also be linked with pelvic floor problems and when suffering from an OBBI/EBBI these muscles go into fight or flight mode causing more tension in the pelvic floor. Pudendal nerve entrapment is also an issue for some. Factor in childbirth as well and our poor pelvic floors can become a mess.

Some ladies are seeing relief from seeing a trained pelvic floor therapist who will work with you to loosen overtight muscles by freeing up trigger points in these muscles. We are often told, particularly after childbirth, that Kegel exercises are the answer but sadly these work in reverse to what your pelvis needs and can overtighten things. You need to work with a therapist on reverse Kegels.

When selecting a therapist ensure that your first few appointments are external treatment only. Trigger points are not only located just vaginally or rectally, they are often external and located in the thighs, abdomen and back.

By loosening these first, you will know if you are ready to move to internal work. Initially you can feel great but be warned, it can make things worse to start with as these are long standing tensions in your pelvic floor that won't give up the fight easily and can increase frequency and pain in the bladder.

Additionally, Amy Stein's book Heal Pelvic Pain has lots of information:

<http://www.healpelvicpain.com/>

There is more information about Pelvic Floor Therapy on the OBBINFO webpage under OBBI General Topics as well as a list of UK and Ireland PF therapists under the link to pelvicphysiotherapy.com.

Pelvic Floor Cushions

For those with a tight pelvic floor and/or who experience a lot of pain when sitting for long periods of time, a pelvic floor cushion with a cut out specifically for the genital area has provided some with lots of relief. It's also useful for travelling as well. Link below for where to order the different types that are available:

<https://thatsexualhealing.com/2014/03/28/pelvic-pain-cushions/>

Exercise

This is a very individual issue and what works for one may cause another to have a bad flare. Certainly, in the early to mid days of treatment, aerobic exercise including body pump classes and running, cycling and horse riding should be avoided as well as Bikram and Ashtanga yoga until you feel well enough to reintroduce it. Swimming pools can irritate as chlorine is a known urethral and bladder irritant. However again this is very individual so if you love to swim and have no problems, keep swimming.

Walking and restorative yoga classes are an excellent start for those starting to heal or who simply want to exercise. After that, listen to your body and add in exercise gradually. Remember if you are attending a group class make sure you tell your teacher you have pelvic floor issues. A good teacher should always offer alternatives and if it hurts – stop.

Urovaxon/Uromune

These are two recent vaccines that have been made available in Europe and the UK for the treatment of UTIs. Urovaxon is specifically targeted at single E Coli infections whereas Uromune is quite different to Urovaxon. It is not targeted primarily at E-Coli but at several pathogens and it is an immunostimulant - it stimulates the bladder's own immune system to work harder to clear bacteria. It should, therefore, in theory be useful against multiple pathogens. It is currently available on a named patient basis from a small number of UK urologists who are running patient trials but please aware that to qualify you must have proven infections cultured on NHS or private standard UTI testing. They will not accept broth culture results or sediment culture results as they are not able to provide these in their clinics for their monthly testing as part of the treatment and trials data.

Both Dr Anderson and Professor Malone-Lee are skeptical as to the efficacy of these vaccines and the makers of Uromune have confirmed that their research and trials have been directed at patients with proven UTIs on standard testing not those with biofilm infections.

Current success rates are 35% for Urovaxon with more research trials being carried out for Uromune in the UK and Spain. Uromune has been used in Spain for quite a while and there is data available on the trial that was carried out there.

Bladder Health UK (formerly the Cystitis and Overactive Bladder Foundation) can provide you with further information on both Uromune and Urovaxon and who to contact in the UK if you would like to be considered for treatment on a named patient basis.

How often should I go to the loo?

For bladder health in general it is recommended you urinate every 2 hours. This prevents the urine sitting in your bladder and allowing bugs to breed and burrow. You should always pee before and after sex and ensure that if you are travelling you have plenty of liquids with you and try to use the loo every couple of hours. Don't sit and suffer because everyone just wants to get there and the next service station is ignored.

Urologists often recommend double voiding which means going for a pee and then 10 minutes later going again in case the bladder did not completely empty. Obviously, you know your own bladder and whether it does empty fully but it may be worth an experiment.

I have booked a holiday/short break – what should I take?

It is recommended to pack meds in hand luggage in case hold luggage goes astray. Make sure you have adequate travel insurance and/or a European Health Insurance card in case of the need for GP or medical assistance whilst away.

- Any antibiotics currently prescribed – always pack enough to cover you in case of travel delays at the end of your holiday
- Any natural supplements you may be taking – D Mannose, Oil of Oregano, Urva Ursi etc. Do not assume you can purchase these in your holiday destination.
- Prescribed meds for other non-related bladder conditions – again enough to cover you in case of travel delays
- Probiotics and Sacchro B – ideally those that don't need to be refrigerated such as Culturelle or Optibac
- Pain relief
- A tub of bicarbonate of soda to help with flares and to alkaline the urine or Cystitis relief sachets
- A mini hot water bottle
- Antihistamine tablets
- Thrush or BV medication
- The latest correspondence from your specialist to your GP (either in electronic format or hard copy). A repeat medication letter from your GP to cover you for non-bladder related meds should you run out
- Rehydration sachets and diarrhoea medication in case of holiday tum
- A meditation or mindfulness app on your phone or tablet to help with stress or flares

Why do I flare when I travel - particularly on a flight?

The mast cells in your bladder react to any form of vibration and can release histamine into the bladder causing a flare up. Additionally, the stress of preparing for a holiday can cause additional histamine release as you worry about being unwell on holiday. It may be worth packing and/or taking an antihistamine for a few days beforehand such as Ranitidine or Cetirizine.

Remember Gut bacteria produce histamine so any change in diet such as on holiday can alter the gut balance causing additional histamine release. Make sure you pack a good probiotic to help settle the gut

I am not from the UK or the USA; can the specialist doctors you have listed help me?

Yes! Please do not worry if you are not in the UK or the USA. Some of the doctors listed below offer international services so they will be able to help you too.

What to expect at your first appointment with Prof Malone Lee or Dr Anderson

When seeing Prof ML for the first time he will ask for a sample on arrival which he will examine under his microscope checking for white blood cells and epithelial cells as a marker of infection. The white blood cells are an indication of inflammation in the bladder showing infection and the epithelial cells show how the body is responding to this infection. The higher the epithelial cell count the more the body is responding to the infection.

Do not worry if you only have low cell counts, the very nature of these types of embedded biofilm intracellular infection mean that the bacteria flux in and out of the bladder wall and the body responds to this accordingly. This is not a standard NHS urine test so he won't be culturing your urine to determine what bugs you have and antibiotic sensitivities. Note, he no longer offers the detailed Sediment Culture. You do not need to stop any medication/antibiotics either bladder related or for other medical conditions before seeing him, just make him aware of what you are currently being prescribed for all medical conditions.

It is best to not drink too much before you see him if possible so that the urine is concentrated. Too dilute and he may not be able to identify the white blood and epithelial cells under microscope.

He will take a history from you of your symptoms etc. he has around 20 questions that he will ask you such as do you get up in the night to pee, does it hurt when you pee, is there pain as the bladder refills, does the pain radiate out and where, do you leak when you cough, laugh, can you make it to the loo when you out the key on the lock, how many times a day do you pee?

All this information you provide him is added to a specific computer programme he has written and based on these symptoms and your urine microscopy he will determine which abs to start you on. Don't be put off that he is typing away as you talk rather than looking at you or that he fires questions at you. He is listening but simply putting everything into your notes.

If you have any recent positive sample test results with you, take them with you but he may not base his prescription on what they say. Please also make him aware of any allergies or any previous reactions to medications. All will impact on what is prescribed. Also always ask him what to do if you do flare on medication and whether the current medications prescribed can be increased in dosage. Ask him to note this in the letter that is provided to you and your GP so you know what to do.

He will tell you to keep in touch with him as it can take several ab tweaks before things settle and it may get worse before it gets better as the bugs will fight back or you will suppress one bug for another to rear its ugly little head becoming dominant. He will give you a letter and send a copy to your GP and will follow up in around 8-12 weeks (with a specific appointment which he will arrange whilst you are there). You will hear the words "dogged persistence" and you will need to adopt this as it can be very up and down. He is available on e mail and if you react to one of the abs you must tell him immediately so he can switch you.

We should add that he has a team of doctors so you may seem him the first time but for follow up appointments, you will be seen by one of his team and then he will pop in at the end to agree the treatment. This is applicable to those being seen on the NHS. If seeing him privately, you will see him each time. For those not able to travel each time to see him, he is able to offer telephone consults but obviously, your urine cannot be checked.

This will impact on whether he is able to change your medication so you may need to factor in travel to him for a urine check. The urine check is very useful as he can track your progress. Be prepared for a graph that looks like a roller coaster (a damped oscillation). Nearly all his patients have this type of graph and ask for it at each of your appointments so you are aware of the treatment pathway.

For international/private patients you will be seen privately in the afternoon/evening at his private clinic in Harley Street so make travel and accommodation arrangements accordingly. Professor ML will see patients from overseas in person. For changes in medication, overseas patients must travel to see him in person. Again, this is due to medical insurance regulations imposed on him. If your GP is willing to work with him from distance, then he may be able to agree a treatment programme of different abs. This should be discussed at your appointment with him.

Please note at present the Professor is not accepting any new NHS patients but is accepting private patients at his Harley Street practice. No children can currently be seen either privately or on the NHS. These restrictions will hopefully be lifted and there are ongoing discussions with the Whittington Hospital where his NHS clinic is located.

Dr Anderson - Please note at present (from March 2017) Dr A is not accepting any new patients whilst she concentrates on new treatment development. Please contact her office for further information and advice.

When seeing Dr Anderson for the first time. All patients must see Dr A in person for their first appointment. You can discuss in advance with her office whether to bring a urine sample with you to your appointment or provide the sample after your appointment. New patients include those who saw her a few years ago, even as a returning patient you will be treated as a new patient.

To start with she will take a full history from you (unless you have provided this in advance by email) and discuss your symptoms both past and present. If you suffer from thrush and are seeing her in person either for the first time or as a follow up, she can swab you to test. She also offers blood tests for thyroid, anemia or hormone issues (at an additional test cost). She is very compassionate and will take a lot of notes but most of all will listen to your history, ask questions and if you are happy to be examined, she will examine you. You must make her aware if you have any allergies or have had reactions to antibiotics prior to commencing treatment.

Once she has your broth culture results and a follow up call has taken place she will issue a private prescription of 2 weeks' maximum in length and advise you of natural remedies to take that can boost your health bladder wise.

Always ask her to send you a copy of your test results so you have them for your records. You then can take them to your GP when the clinic is closed for holidays if you need additional medication.

If after the two weeks you are still experiencing symptoms, please contact her office with a detailed email explaining what your symptoms currently are. She will revisit your broth results and may issue a further 2-week prescription for another antibiotic. If after this period, symptoms still linger, you will need to do another broth culture and it may mean a further change of abs. Again, ask for the latest culture results for your records. However, once your bladder is stable in treatment, if you so wish, she will write a letter to your GP explaining her treatment and the broth culture results.

Based on this letter, you can then work with your GP to provide further prescriptions. Due to GMC restrictions on antibiotics she is only able to issue 2 weeks of medication at a time.

Above all, you must keep in contact with her by email to advise her of your progress, flare ups or even when things have settled. This is critical for her patient care records as well as maintaining your treatment relationship with her.

Vik Khullar

Mr. Khullar is a Consultant Gynaecologist and Obstetrician at St Mary's Hospital, London part of Imperial College Healthcare NHS Trust. Mr. Khullar also has his private clinic in Central London at 19 Harley Street, London. He treats patients for chronic embedded urinary tract infections by usage of high dosage rotational antibiotics (but may not necessarily offer long term abs such as Prof ML does). He will also look at patients with possible histamine issues and treat accordingly. He has produced studies showing biopsies of bladders that have high colonies of biofilm colonies embedded into them.

Be warned, his wait list is very high for both NHS and Private treatment and if in treatment on the NHS it is likely you will be seen by one of his team of doctors rather than VK himself.

Susie Elneil

University College Hospital in London (UCLH) in London have recently opened a chronic recurrent UTI clinic treating patients with infections that cannot be cultured under normal urinary testing standards. This clinic is headed by Susie Elneil and the team includes PHD students trained by Prof ML. Treatment is with high dosage antibiotics.

This clinic is not attached to the Urology department at UCLH. Miss Elneil and the team are in regular contact with Prof ML and many of Miss Elneil's patients over the years have been referred onto the Prof before this NHS clinic was opened this year.

She also sees private patients at her consulting rooms in Devonshire Street. Current wait time for a first appointment is around 11 weeks for NHS referrals. Please note that her clinical practice name is Sohier Elneil, not Susie when seeking a referral.

Its recommended that to maximise the most out of your appointment with any of these specialists, you may want to send each specialist a short medical history relating to your bladder in advance of your first appointment. This will save time and give them some background info in advance. Admin have had experience of specialists noting that they wished more patients would do this so it gives them an understanding before the relationship begins. Email details are at the end of these notes with the contact details for each specialist if you wish to do this. Always take it with you on the day of your appointment in case it has not been placed in your file.

Additionally, make sure after each appointment you have copies of all test results previously ordered by your specialist and discussed in your appointment and ask that you are copied in on any correspondence with your GP. If with Prof ML or his team, before leaving make sure you have your latest urine microscopy graph.

When and why should I contact my specialist between appointments?

All the specialists have advised that you should contact them when the following occurs:

- emergency flares – noting your symptoms and what if anything precipitated the flare
- failures of treatment on current antibiotic regimes
- adverse drug reactions
- repeat prescription requests (unless your GP can prescribe the necessary medication)
- Change in personal details such as address, telephone number, email or change in GP

For those newly in treatment when infection response can change rapidly, you will be asked to provide a regular update so that medications can be changed or if needs be, you go back to the clinic for further investigation of the urine or submit a new sample for testing and a discussion of symptoms.

All specialists require these responses as they are needed to maintain scrupulous clinical safety records and to monitor your progress in treatment. You may not be aware that your email to your specialist is always included in any reply from them and will be sent to your GP for their clinical records. All other issues such as queries on lifestyle (including your sex life) or diet should be discussed at your next clinic appointment but please be mindful that your specialist is a clinician not a lifestyle guru and you should seek advice either via one of the Facebook groups, these FAQ notes or through your own research.

Patients are lucky in that their specialists do offer an email service to contact them. However, it cannot be stressed enough that this service should not be abused. Keep your note short and succinct relating to the bullet points above. It's completely understandable that you feel upset and concerned about new symptoms or a flare but our specialists have reported regular abuse of the service which could result in its withdrawal which benefits no-one. If in doubt about when to email, always ask at your face to face appointment.

Treatment during Specialist holidays/Public Holidays or periods when clinics are closed

Where possible, the specialists try to provide good notice of clinic closures so that patients can request repeat prescriptions in advance but when the clinics are closed, for NHS patients under the treatment of Prof ML, if his team are doctors are still operating you can contact the clinic by email to report flares in treatment, issues with medications and repeat prescriptions can also be requested. For private patients, the NHS Drs are unable to help with flares and no new medications can be issued. They can, however, issue repeat medications. For patients of Dr Anderson, Miss EN or VK, please email the clinic as normal but there may be a delay in responding.

It is advised that patients should seek the assistance of their GP who can issue temporary medications. Whilst we know this is difficult as many GPs are not supportive of treatment, they have a duty of care to you. Please take letters from your specialist along with any test results so that your GP can see what has been prescribed and any bacteria identified along with suitable medications to treat these. For severe flares, worsening symptoms and reactions to medication, please go to A&E or the Emergency room and take your latest letter from your specialist along with the current medications you are taking.

Try not to panic when the clinics are closed and in advance make sure you have enough medication to see you through the period of clinic closure. Stress can often trigger flares. We should accept that our specialists too need holidays given the many hours that they dedicate to our treatment during the year.

Obtaining Prescriptions and Repeat prescriptions

If you are being treated by Dr A, your prescription will always be issued as a private prescription and posted to you. At present, she is only able to offer an initial prescription of 2 weeks in length based on confirmed infection. If you do not respond to these antibiotics, then a follow up consult may need to be arranged to discuss a change in prescription but again, this will only be for a maximum of 2 weeks. Once you are stable in treatment, she will be able to write to your GP so that medication can continue via your GP.

Prof ML offers private and NHS prescriptions. If private, then a private prescription will be provided and a letter sent to your GP. As above, if costs are prohibitive then you will need to work with your GP to convert these prescriptions into NHS prescriptions. If seen via the NHS, then you will be issued with an NHS prescription. The building where his clinic is located has a pharmacy on the ground floor and we recommend you visit this pharmacy after your first visit as they always keep in stock the medications he prescribes so you should be able to obtain the medications needed without delay.

We also recommend for international patients you have your prescription filled in the UK as medications are often either not available in the same strength or available at all in your home country although it is appreciated that costs for antibiotics vary from country to country.

If you require a repeat prescription, then you must email Prof ML requesting this in good time and give him an update on symptoms/progress as well for his records. Remember he has separate email addresses for Private and NHS Patients so use the one appropriate to you. Prescriptions will be posted to you or, if you live close to the London NHS clinic at Hornsey Medical Centre then they are taken down to the pharmacy on the ground floor after 5pm each day and can be collected from there (NHS only). The pharmacy is open until 10pm Monday to Friday and 9pm on Saturdays and Sundays. The Pharmacy contact telephone number is 020 3074 2700.

For those in treatment with Ruth Kriz in the US, Ruth sends the prescription medication right to the pharmacy of your choice whether based in the US or internationally. Over the counter supplements are mailed directly to you. Refills are taken care of by the pharmacy who will call Ruth if you run out. The new compound formulas for instillation are mailed to you.

Why are my medications being reduced/stopped?

If you are experiencing good progress on your antibiotics, the dosage may be reduced or stopped to see how your bladder responds. Don't panic about this. Our specialists need to test this to see the response. If things are good, then you can continue off the antibiotics or take the lower dosage. Prof ML states that if after 12 weeks there are no further symptoms then antibiotics can be stopped but at the first sign of trouble, they must be restarted. However, if after a few days/weeks, symptoms return then you may be asked to retest or be given new antibiotics. Dr A does not offer long term antibiotics due to GMC restrictions so if your GP refuses further antibiotic treatment, you will need to contact her to discuss alternative treatment.

No-one wants to stay on antibiotics long term so look at this as a positive. You have come a long way and made progress for this to happen. If things slip, don't be disheartened. Your specialists will continue to fully support you and who knows, in a few months, you can try again and hopefully there will be a different outcome.

Prescriptive medication advice on FB groups

If you are a member of any of the FB support groups, please do not ask for advice on prescription medication and/or increasing/decreasing dosages on the FB groups. No members are medically qualified to provide advice on prescription meds and the groups do not hold the appropriate qualifications/training/insurance that qualified medicals specialists are required to have. All queries about prescription medication and issues relating to treatment must be directed to either your specialist or in their absence your GP/Physician or in an emergency the appropriate medical professional within A&E or the Emergency Room. Whilst we enjoy the support of our specialists in all that we do, they have made it clear that we must not provide any prescription medication advice to members and these groups have always been run on this understanding.

Furthermore, we should always be mindful of what we post and how it affects others in terms of medication discussion. Medications are prescribed by specialists for a specific patient's treatment and that patient may have no side effects in comparison to others so please always think before about what you write about this medication when talking about your own experiences as another person may be seeing a lot of benefit from the medication or have had it newly prescribed and comments can cause fear and may prevent people from taking medications. People should always discuss any potential side effects with their specialist during their appointment and read the explanatory leaflet provided when the medication is issued by the pharmacy/chemist. If you do experience an issue, always contact your specialist for advice.

Further Support Groups available to OBBI FB group members

Members of the original OBBI Support Group have created other support groups and you are really encouraged to get involved in these as well. Like the OBBI FB group, these groups are secret groups so none of your family or friends who you are linked with on FB will be able to see what you post.

Women and Men Support Group

A mixed group for patients with either Professor Malone Lee, Dr Anderson, Vik Khullar or Susie Elneil. The default will be to join you to both support groups unless you specifically ask us not to do this. Please contact Kirstin Roma Isabella Lavender by personal message if you wish to join.

Women & Hormones Group

A group for women experiencing hormonal issues at whatever age that are impacting on their bladder and lives in general. Contact Kirstin Roma Isabella Lavender or Citizen Jo Jo by personal message to be added.

Under 25s Bladder Support Group

This group says what it does on the tin, its for those under 25 who want to talk about their bladder, share stories and hopes and fears and how its impacts on their lives and just chat about their lives with other members. Contact Amy Kraven by personal message to be added.

Functional Medicine Group

Do you believe IC is an embedded/biofilm infection? Maybe you also have other autoimmune diseases such as Hashimotos, PCOS etc., or suspect having them. Are you sick of being sick and frustrated with the conventional medical approach? This group was created to connect all the dots and get to the root cause/s, using the functional medical approach. Contact Navita Sahota, Teresa Little or Charlotte Louise Parfitt-Reid by personal message to be added.

CUTIC (Chronic Urinary Tract Infection Campaign)

CUTIC is actively campaigning to bring about change in the medical world for recognition that a Chronic Urinary Tract Infection is not the same as an acute UTI infection and current prescribing and treatment guidelines need to be changed globally to recognize chronic UTIs and bring about total diagnostic and treatment changes. This is a very energetic, talented group who welcome people from all over the world and we really recommend you join. You will have the opportunity to get involved, have your say and add ideas and develop programmes at a local and national level to campaign for changes in the testing and treatment of recurrent and chronic UTIs.

<http://www.cutic.co.uk/about>

OBBINFO.com

The OBBINFO.com webpage has been developed with far more detailed information than these introductory notes can provide. The headings should be self-explanatory and we have added two new features – Grabsheets which in simple detail explain the most common questions asked on the group and Factsheets which go into more detail about some of these questions and other topics. A link to the webpage is below. Do please bookmark this site and save it as a favourite as it is updated continuously and these notes are also found here.

<http://obbinfo.com>

Useful Doctors/Practitioners contacts:

These doctors are the only practitioners we have identified who will treat your 'Interstitial Cystitis' as a biofilm infection so it is crucial to book an appointment with them as soon as possible to begin treatment. Most group members are under one of these doctors and are seeing remarkable results.

UK

Private only:

Dr Anderson (Staffs Dr) – Currently not taking any new patients (as from March 2017)

01782 703007

<http://www.focusmedicalclinic.co.uk/>

email: contact@focusmedicalclinic.co.uk

The cost of consultations is listed below;

A face to face consultation is;

30 minutes = £120.00

45 minutes = £160.00

60 minutes = £195.00

Follow up consultations conducted via telephone;

15 minutes = £60.00

30 minutes = £115.00

45 minutes = £155.00

60 minutes = £185.00

In addition to the above, if all are paid for as a package before a face to face consultation or if a sample is posted you can request an extra 15 minutes onto your follow up consultation. The cost for this would normally be £60.00

Please note that if a consultation extends from the original booked time and the extra 15 minutes you will receive an additional invoice to reflect this. Due to medical insurance regulations, Dr Anderson will only treat patients from UK and Ireland.

NHS and Private/Medical Insurance:

Professor Malone Lee (London Dr) – secretary Martel

NHS Patients - Tel 020 3074 2256, Fax 020 3074 2401, Email lutscommunityadmin.whitthealth@nhs.net.

Private Patients – Tel 07568 403211 Email: profjmlclinic@tenharleystreet.com

Martel Daley-Peat is his NHS and Private Patient secretary.

If you want to book an appointment with him on the NHS or Privately using UK Insurance or self funding, you will need a referral from your GP. The OBBINFO.com webpage has a specific section for Prof's research papers and those recommended to take to your GP are: The Treatment of Lower Urinary Tract Symptoms Prof JML clinic for GPS and Patients and "The treatment of chronic urinary tract infection in clinic" by Professor Malone Lee.

His NHS clinic is located at Hornsey Neighbourhood Central Health Centre, 151 Park Road, London N8 8JD

<http://www.nhs.uk/Services/clinics/Overview/DefaultView.aspx?id=90175>

For private and self funding patients, charges are: New patients £250.00, Review patients £200.00, Telephone consultations £75.00, Email advice £20.00. Please note his new private clinic is located at 10 Harley Street, London (nearest tube Oxford Circus). Patients needing a urine check but no consult will be charged £25.00 and will need to visit the NHS clinic for this. Martel will arrange this appointment with you, don't just turn up at the clinic and you will receive an email from the Professor around 24 hours after you provide your sample.

<http://www.tenharleystreet.co.uk>

Vik Khullar

NHS

St Mary's Hospital, Paddington, London:

<https://www.imperial.nhs.uk/our-services/gynaecology/urogynaecology/clinics>

Private:

Tel 07500 33 4000

Landline 020 8299 2959

Fax 020 8299 0169

Email: vkhullar@nhs.net

Susie Elneil

University College Hospital London (NHS). The code for her clinic is SE2UG for recurrent/chronic UTI. When seeking a referral her clinical practice name is Sohier Elneil not Susie Elneil. Make sure your GP puts this in his/her letter.

<https://www.uclh.nhs.uk/OURSERVICES/CONSULTANTS/Pages/DrSohierElneil.aspx>

For private referrals, her rooms are located at 16 Devonshire Street, London.

Secretary Claudet: 020 7387 7055 elneil.pa@btconnect.com

USA

NP, Ruth Kriz.

Nurse practitioner Ruth Kriz works out of the Washington DC area. 2604 Connecticut Avenue NW, Suite 300, Washington, DC 20008. She can see patients in her office, skype, or do phone consults. You do not need to see her to be treated. She has successfully treated many patients globally. You can call her office to book an appointment and ask for rates.

001 202-714-2415. You do not need to have any tests before seeking your first appointment. Ruth will most likely order tests for you, then treat based upon the results.

<http://ruthkriz.com/>

United Medical Labs

United Medical offers specialist culturing in the USA. They accept samples from International samples via Fedex overnight. (Samples should be placed on icepacks for mailing).

www.unitedmedicallab.com

Pathogenius

Pathogenius offers advanced Molecular testing of urine which is the next generation of urine analysis. To submit a sample, you must be registered with a US practitioner recognised by them. They will currently not offer analysis to international patients.

<http://www.pathogenius.com/>

If you are from outside the UK or the US please do not worry, we can still help you, please email contactcutic@gmail.com

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