



Continence and bladder problems

Chatroom

8 December 2004

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8 December 2004 – 10am to 7pm

The experts:

- **Clare Lennon**
MS specialist nurse (10am – 3pm)
- **Kim Gandy**
MS specialist nurse (10am – 1pm)
- **Annette Leach**
MS specialist nurse (2pm – 7pm)
- **Vinay Kalsi**
Urologist (3pm – 5. 45pm)

Ricky: [question sent in advance] I have been diagnosed with MS for quite a while now but I must emphasise, that I actually do not suffer!! My job is a firefighter so therefore I am obliged to keep fit (mainly to stop the doctor pensioning me off!!). As a result I do a lot of running (marathons etc). The one thing I do have is a very weak bladder and I suffer from the condition known as 'Joggers trots'. You can imagine this during a run! I try to do all my training in the dark for obvious reasons, however racing is always done during daylight hours!! I have spoken to my GP and tried several tablets that were supposed to help the bladder, unsuccessfully. Is there anything else out there I should try?

Kim Gandy: I wonder if you have seen a continence advisor or a urologist for a more in depth assessment of your bladder and pelvic floor? Your GP can refer you on to both these professionals. I would start with the continence advisor, who is a nurse who specialises in helping people with bladder and bowel problems. She/he will scan your bladder to see if you are holding on to urine (ie, have residual urine), as this will have an impact on bladder function. It is always good practice to have this simple procedure prior to trying medication. It would be helpful to determine why you need to go to the toilet so often. The urologist can arrange a more in depth bladder assessment using a technique called urodynamics. Depending on the outcome of your investigations, the following may be treatment options:

- If you are found to be holding on to urine, then intermittent self catheterisation prior to running may resolve the problem
- If your pelvic floor is weak, then being taught how to do pelvic floor exercises may help
- Other medication may be useful, though without knowing what has been tried, I can't really comment on this

If after all this intervention things have not improved for you, then you can ask for a specialist referral from your GP to a neuro-urologist at a center such as the National Hospital in Queen Square in London

Simon - MS Trust: Hello Tina, do you have a question for Clare or Kim?

Tina: Other than oxybutinin what can I take for bladder urgency?

Julie: Hello all. I understand my problem may be failure to expel full contents at one time. Any suggestions?

Tina: I also have same problem as Julie and keep getting urinary tract infections (UTIs). I take trimethaprim at night to try to stop this

Kim Gandy: Hi Tina. Has your doctor tried to find out why you are getting infections?

Tina: Yes, its because my bladder does not empty properly

Kim Gandy: Have you seen a continence adviser, or had a bladder scan?

Tina: Yes, and they say if it keeps happening I will have to self catheterise

Kim Gandy: How do you feel about this technique?

Tina: I do not want this at all. Is it happening because I cannot empty my bladder or could it be another reason

Kim Gandy: It is most likely happening because the nerve messages are not giving the right message to your bladder to contract, thus you are holding on to urine. This is a common problem that is due to MS

Tina: I drink lots of fluids to try to avoid infections. I take 10mg slow release pm 5mg am. Is there any other drug?

Kim Gandy: So long as you have a reasonable post void residual (100mls) then you will continue to get infections, as the stale urine is a breeding ground for bugs. There are no drugs that help to remove the urine and it is important to think preventatively as well. If you continue to get infections then this may have an effect on your kidneys in the longer term, so it is important to find away to remove the urine. This is why intermittent self catheterisation is being suggested

Julie: Can Tina's drug be taken as and when or does it have to be continuous? My problem tends to be a day or so and then settles?

Clare Lennon: Julie, you say you have a problem with not fully emptying your bladder at one go. I wonder if you have been seen by a continence advisor and had an assessment and a bladder scan?

Julie: No, I've not seen anyone other than my GP.

Clare Lennon: If you have been through this route you can try tapping gently over your lower abdomen, or bending forward whilst sitting on the toilet (double voiding). You may also be helped by using a Queen Square bladder stimulator - a vibrating device which one places over the lower abdomen to aid emptying. Your continence advisor can provide information about this for you.

Julie: Presumably reducing fluid intake is not a good option as can cause other problems plus increase infection risk?

Clare Lennon: If persons do retain a lot of urine, then sometimes they are taught to empty their bladders via a small catheter, a procedure known as intermittent self catheterisation. Again you can discuss this with a continence advisor.

Tina: OK. I'll keep doing all things am told and try to keep catheterisation off as long as possible.

Julie: Same goes for me. Thanks for your help. Have to sign off now. Bye

Kim Gandy: Don't be frightened about intermittent self catheterisation. Many of my patients who use it they say I wish I had started this sooner, as it has improved my quality of life, and they feel much better in themselves as they no longer get infections

Sue: [Comment sent in advance] The subject of bladder problems is something I can comment on. I have suffered with incontinence problems for ten years+. Medication did help for a time, but when the effects wore off the urgency appeared to be intensified. I was referred to the Urology clinic for test to determine the strength of the muscles. These were weak and it was decided to use a stimulating machine to strengthen these muscles. It worked. I purchased a machine and now use it twice a week to maintain the muscle strength.

I had stopped using it but on resumption I found the control that had slipped away was rekindled very quickly. I suppose this stimulation would not be suitable for everyone, but I have benefited and for that I am most sincerely grateful.

It does help if water is consumed - approx one litre per day. Urine is then not so concentrated and does not irritate the bladder. Also, the stimulator reminds you of how it feels to tighten these muscles. I found this especially helpful.

Simon - MS Trust: Hello Jim

Jim: Hi there

Simon - MS Trust: Do you have a question for Kim or Clare?

Jim: I have been self catheterising for quite a while and wondered how often I should have a urine sample tested

Kim Gandy: Jim you do not need to have a sample tested, unless you suspect you have a urine infection

Jim: Thank you. Someone told me I should have one done at least twice a year

Kim Gandy: Do you know why they said this?

Jim: No, it was the continence nurse. She did not say why it was when I first started and I just thought it was the done thing

Kim Gandy: It might be that in your area that they have a protocol that suggests this, so it might be worth checking with her/him again. Do you know when you get an infection?

Jim: Yes. I have not had many but can tell because I start feeling a bit grotty

Kim Gandy: Then at least you know you can get treatment as soon as possible, so I would feel you do not need to test at random times. What is the outcome of the tests? For instance, if you are found to have an infection but are showing no symptoms, then would your continence advisor suggest that you are treated with antibiotics?

Jim: Thank you Kim. I'm off now but will log in later

Mina: [question sent in advance] My husband suffers from MS and he is in a secondary progressive stage and wheelchair bound. In October this year he was unable to pass urine and to me he looked very uncomfortable. He desperately wanted to go to the toilet but nothing happened. I finally called an ambulance and took him in hospital and they put the catheter to drain the urine and we were allowed to come home. The doctor told us that his bladder had gone into spasm that is why he has this problem. My husband could not get used to the catheter and his district nurse told us that they are not going to remove it as they may have to put it back. He will have to have it for the rest of his life. I would like to know more about the problem and how it is dealt with.

Clare Lennon: Urinary retention does tend to happen to many patients with MS. It is always useful to know the cause eg spasm or sometimes it can be the side effect of certain medications such as amitriptyline. You could ask your GP to refer your husband to a consultant urologist for further advice and investigation. Sometimes, if the bladder won't empty fully and a person can't tolerate a urethral catheter, then a suprapubic catheter (one inserted into the bladder through a small insertion in the abdominal wall) may be a better option. It is always good to know the causes and what the options are.

Chris: I'm concerned about becoming resistant to anti-UTI antibiotics

Clare Lennon: Hello Chris. Why are you concerned about this? Are you using antibiotics frequently?

Chris: Whenever my urine is dark or smelly I'm afraid of it causing relapses by urinary tract infections so I self-catheterise.

Clare Lennon: It is advisable to drink approx 2 litres of water a day to help prevent infections. You could always try drinking a glass of cranberry juice (200mls) a day too or take a cranberry tablet. You are right to be concerned about the effects a urine infection can have on your MS. Perhaps a change of type of catheter might also help?

Chris: I drink cranberry juice a lot. I find it great for keeping the bladder clean

Clare Lennon: That is good, but a glass (approx 200mls) a day is sufficient.

Tracey: I have a bladder infection at the moment and my doctor has given me some antibiotics which I have used and they were successful. I also do self catheterise. I know I don't drink enough throughout the day, I never have but I am at the water, water with a hint of grapefruit in it and decaffeinated tea.

Kim Gandy: Tracey do you get many infections?

Tracey: My last lot of antibiotics were back in February. I've only got six tablets left, so will have finished them in three days

Kim Gandy: That's OK. It's just that you shouldn't get many infections with self catheterisation, and if you were then you may need to be reviewed. Clare has already just covered how much you should be aiming to drink

Chris: What is ISC? I must try to drink more.

Clare Lennon: ISC stands for intermittent self catheterisation, which is the same as self catheterisation

Chris: I use Lo Fric, lubricated with clean water. I find this very convenient

Clare Lennon: This should be a good catheter. Many of my patients use it too. Perhaps you could have review by your continence advisor to check out your technique again.

Tracey: I only really self catheterise when I am going out. I don't do it every day but when I do it I only manage to get out about 50ml. I am on trimethoprim

Kim Gandy: Have you been reviewed by your continence adviser recently?

Tracey: No I haven't.

Kim Gandy: Are you on any tablets for your bladder?

Tracey: No I'm not :-)) I think my problem is that I don't drink enough throughout the day, but I am really trying and my husband is forever asking me what I have drunk. Do you think I should self catheterise more frequently? But I only really do it if I am going to the pictures or a long journey. I also use pads for ease of mind if caught short whilst out.

Kim Gandy: Sometimes bladders react differently. Sometimes the problem can settle down. If you are experiencing a lesser residual than you used to then it would be useful to be reviewed by the person who started you on intermittent catheters. I am assuming this is your continence nurse

Chris: I just want to say these email-ins are great, thanks everyone

Simon - MS Trust: Thanks Chris. There'll be a transcript posted on the site in a few days

Mike: For a male, how are definitions made between prostate and MS causes?

Clare Lennon: Basically, we should not presume that a male with MS who has bladder problems will have them because of his MS. One should always be given a good assessment by a continence advisor in the first instance, and if necessary referred on to a consultant urologist for further investigation. Concerns would arise if the male was not emptying his bladder fully and particularly if he was 40+

Mike: If I bend shortly after, I squeeze more out?

Clare Lennon: If you have to bend forward to squeeze more out, you are probably not emptying your bladder fully. Have you had your bladder scanned to determine this?

Mike: I had this about 18 months ago, and there was plenty left, but shortly after could go again

Clare Lennon: If there was plenty left, ie over 100mls, you may be suitable to be taught to self catheterise. But as I said, if you are not emptying fully, you should be further investigated by a urologist. Could you discuss this further with your continence advisor or your GP? It would be good to know if your problem was indeed MS related and not because of your prostate.

Mike: OK thanks, I will see my continence nurse and get re-checked

Alan: [Question sent in advance] I was diagnosed in March 2004 and have contact with the ms nurse at the Great Western Hospital in Swindon. I am having urinary problems and bladder control problems. I take 2mg of detrusitol daily. I am being referred to a specialist early in the New Year but would like a happy and dry Christmas and I don't wish to upset my four year old twins. Any natural suggestions? Also I cannot achieve erection for sexual gratification for my wife, again any suggestions.

Clare Lennon: You could ask your GP to prescribe you detrusitol XL 4mg in the morning. This is a slow release version of detrusitol and is some time more effective. As regards your erectile problem, you could – at the same time – discuss with your GP being prescribed with Viagra, which is available for men with erectile problems

Chris: On continence, my advisor has me on 4-ish senna every 3-4 days. It works. What's your opinion?

Kim Gandy: Chris, if senna works then that's fine

Chris: I'm worried that in the long-term it will not be effective and I'll need a more radical approach. I am scared

Kim Gandy: You will need to tell me a bit about your difficulties to help you further

Chris: Without senna I'm constipated for days. I'm just concerned on what to do long-term,

Kim Gandy: There are other aperient type drugs that you can use, but if you find that senna is working, then it might be wise to stick to it

Kim Gandy: You mention long-term effects, have you read something that has worried you?

Chris: I'm concerned that long-term effectiveness diminishes if relied on 100%

Kim Gandy: This can happen, but you still have to go to the toilet now, so I would suggest you discuss this with your GP as well as your continence nurse. You may be worrying about something that will never happen to you.

Craig: I have currently a bladder infection which has got resistant to drugs and have had various dermatological problems. Can you suggest anything?

Kim Gandy: How often do you get infections, and do you know what is causing them?

Craig: All the time. No I don't

Kim Gandy: Have you had a bladder scan or seen a continence nurse?

Craig: I constantly catheterise and I feel sure I picked up my infections from hospital by having an inbuilt catheter in hospital can anything be done?

Chris: On urinary tract infections, is it wise to give myself antibiotics (once every 4 months-ish) or risky?

Kim Gandy: If you are having lots of urinary tract infections this could be related to not moving your bowels so well as well as to your bladder function. Again you should go back to your continence adviser and discuss things.

Chris: I'm a worrier, yes. And worry on doing right things now so not make it harder later

Kim Gandy: You can always ask to be seen by a specialist nurse dealing with bowel dysfunction.

Chris: I am actually in Hong Kong. There's good care here but always like more opinions and knowledge

Jay: Hallo everyone. Does any one here take trospium or detrusitol?

Clare Lennon: Hello Jay. I don't actually take it personally!, but some of my patients do. Do you have a question about these tablets?

Jay: I find they all have a lot of side effects. Trospium causes bad flatulence and headaches. Detrusitol is not so effective.

Clare Lennon: Yes, bladder medications generally have side effects, most commonly dry mouth. You could discuss with your GP alternatives such as Oxybutinin or Lyrinel XL, which is a slow release tablet. This might suit you better than the others.

Chris: I take Desmopressin nasal spray before bed, but get up twice. Is it bad for sleep?

Kim Gandy: Chris, desmopressin should be stopping you getting up to the loo overnight. Has it reduced the number of times you go?

Chris: It's worse without it. I used to take Oxybutinin too at night, but seemed marginal

Kim Gandy: Do you reduce your fluids while you take desmopressin?

Chris: Well, I try to drink less for two hours before bed.

Kim Gandy: I think it is recommended that you do not drink for this length of time, and that you do not drink for eight hours, while you use desmopressin

Richard: I have been given some sheaths to put on and then to be able to pee into a bottle but can't fit them. Any advice please?

Kim Gandy: Richard can you tell me a bit more about the reasons for using a bottle and what type of sheath you use?

Richard: I have to go more often than usual and have trouble getting up and redressing. I have Conveen sheaths

Kim Gandy: Do you use a leg bag? Have any other sheaths been suggested to you? Who is your contact for advice? Is it a district nurse, or continence nurse?

Richard: Yes I have leg bags. No other sheath has been suggested and mainly I see the district nurse.

Kim Gandy: You may find a different make of sheath is helpful. There are so many different makes, it is best to see a selection so that you could see which would be better for your particular needs. The Continence Foundation (www.continence-foundation.org.uk) could advise you further. Or your district nurse may be able to ask the continence adviser to help.

Richard: The problem I think is the fact that they are like a condom and to put one of them on you really need an erection, which is something I don't get.

Kim Gandy: You should be able to fit a sheath with a flaccid penis. It may be that you have never been measured properly. I do suggest that you ask for a more specialist nurse who can help

Richard: Thanks Kim, I will get on to her straight away. Bye

Simon - MS Trust: Thanks to Kim who has now left the room.

Nichola: I have an indwelling catheter, and have had for several years. Is there any advantage in suprapubic catheters?

Clare Lennon: There are some advantages of using a suprapubic catheter over a urethral one: they tend not to get caught or kinked so easily, and are therefore good for those persons who are wheelchair bound. They are also more convenient for sexual intercourse. It all depends on what problems a urethral catheter is causing.

Nichola: I didn't know if you've got less infection

Clare Lennon: Sometimes this is true.

Nichola: I'm not sold on the idea. I'm not sure that the benefits of worth the hassle of having an operation. Sex with the urethral catheter doesn't seem to be a problem

Clare Lennon: If your urethral catheter is not causing you too many problems, then I can see no reason to change to a suprapubic one.

Nichola: Thanks for that

Mick: I've heard about cannabis as a treatment for bladder problems. Is that a real thing or just web gossip?

Clare Lennon: Trials have taken place, but as yet it is not on prescription.

Mick: How does it help?

Clare Lennon: By reducing the feelings of urgency and frequency.

Mick: Thanks

Simon - MS Trust: Hello Jude. How do bladder problems impact on your day to day life?

Jude: I find I am always looking for a toilet and am loath to go somewhere new in case I can't find a toilet. This is particularly bad when abroad on holiday. I do use catheters and am waiting to be reviewed by a continence nurse

Clare Lennon: I'm sure most people with MS can relate to your problem. If access to toilets is your main concern, then in this country a key for disabled toilets is normally available from local authorities, such as the Citizen's Advice Bureau, DIAL offices etc for approx £3. I'm not so sure about abroad. Perhaps your travel company could advise or you could contact www.continence-foundation.org.uk or www.incontact.org. However, I would hope that you are in touch with a continence advisor who could assess your problems and advise on treatment options to help you.

Jude: I didn't know about a key for disabled toilets and will contact my local authority. Thank you

Mick: I know what you mean, Jude. Knowing where the loo is is *the* most important thing. I'm not happy in a new place until I know the route to the loo

Clare Lennon: Absolutely, Mick. Think about getting a key.

Kate: You can get a card from the MS Society. It says "Please help me. Because of an illness which is non infectious I need to go to the toilet urgently. Thank you" in English and three languages

Clare Lennon: Kate, you are absolutely right about the card from the MS Society. I do give it to patients.

Mick: I've not felt comfortable with the card - though maybe abroad. What are the languages?

Clare Lennon: I haven't got one in front of me, sorry

Mick: Didn't RADAR do a key?

Kate: I have a RADAR key. Still have to find the toilet through. Think RADAR is a national scheme.

Simon - MS Trust: Mick, RADAR does operate a National Key Scheme giving access to locked public toilets. There's info on their website at www.radar.org.uk. Go to the list at the bottom of the About Us section

Mick: Thanks Simon

Jude: I have to go now but what I've learned is useful. Speak to you next time. Bye

Simon - MS Trust: Thanks Jude

Brian: Hi everyone. My daughter has primary progressive MS. She is prescribed methotrexate but has difficulty with urinary infections that lead to incontinence. Trimethoprim is good to control incontinence but can only be prescribed occasionally due to incompatibility with methotrexate. Does anyone have the same experience or can anyone advise alternative forms of treatment?

Clare Lennon: Hi Brian. I can't answer that one I'm afraid. I don't have any patients on methotrexate. This is a good question for the consultant who will be on between 3 and 5pm. Presumably, your daughter is under a local neurologist who could also advise or a urologist?

Brian: Yes, but I have to say, not very helpful. Will obviously ask on next visit in 12 months time! Also, if goat serum shows signs of promise, why the hell aren't trials scheduled for primary progressive MS? It's a crime! Primary progressive seems to be always the poor relation in terms of research

Clare Lennon: There are certain centres who are looking into proper trials.

Brian: Can you advise which, Clare. My daughter is desperate to try it. Are there any private avenues available? How can the Osmond get hold of it or does celebrity status open doors?

Simon - MS Trust: Brian, so far there has only been one trial of goat serum in MS - in London - which is due to report next year. This looked at secondary progressive MS. There is another trial planned, to look at treatment of acute relapse.

Brian: Yes, I know Simon, but every day that passes for my daughter is a day too long

Simon - MS Trust: There is more information on the drug and the trials at the website of the manufacturer - www.davalinternational.co.uk

Brian: Appreciated. What I would like to know though, is why some people were able to get it on informed consent in the early days and now you can't

Simon - MS Trust: According to Daval's website, informed consent access has been discontinued during the trials. Although anecdotal evidence suggests a general improvement in symptoms, I've not heard anything specific about goat serum and bladder problems

Brian: Yes, but why when so many people are desperate for the opportunity? Nothing else seems to work!

Clare Lennon: I can understand your frustration, Brian, but rigorous trials must be undertaken first. Have you heard of it helping any specific symptoms?

Brian: Only anecdotal evidence Clare but that is better than none

Simon - MS Trust: There is a new group set up that shares your frustrations and seeks to raise the profile of the drug. See www.mymultiplesclerosis.co.uk/aimspro.html

Brian: Thanks Simon

Caro: Hi Clare. Is my weakened bladder the result of kids, MS or both?

Clare Lennon: Hello Caro. Yes, it could be caused by both. Childbirth can weaken the pelvic floor muscles. That is why you need a proper assessment in the first place.

Simon - MS Trust: Hello Frances

Frances: Hello. I have bladder problems. Could they be caused by diabetes?

Clare Lennon: Hello Frances. The simple answer is yes.

Frances: It takes ages to empty my bladder sometimes. I have had insulin dependent diabetes for 30 yrs+ plus neuropathy

Clare Lennon: Have you ever been referred to a continence advisor for assessment and advice about this hesitancy to empty your bladder?

Frances: No, I haven't pursued the problem. I'm seeing a neurologist in February though

Clare Lennon: It does sound as if you need to see a continence advisor for an assessment. Could you ask your GP to refer you to one prior to your February appointment? Help could be close at hand if only you could access it. You can always refer yourself. You could telephone your local hospital and ask to be put through to the continence service.

Frances: I'm on NHS core collaboration primary care. Know people who could help maybe

Clare Lennon: That is great. It would be very good if you could have your bladder scanned soon, to ensure that it is emptying. It may not be emptying properly. Do you get many urine infections?

Frances: Only about one per year if that

Clare Lennon: That is good, but it would be even better if you did not get any. Please do ask your GP to refer you or refer yourself.

Frances: I will contact the continence department, if Bury PCT have one

Clare Lennon: Great. I hope you get advice and help soon.

Jay: Going back to earlier comments re drugs, should you not drink with desmopressin? Is the spray better than tablets?

Simon - MS Trust: Jay, we're looking into this for you

Jay: Thanks

Clare Lennon: Jay, it is stipulated that if you are taking Desmopressin, either tabs or spray, you should limit your fluid intake to a minimum from one hour before taking your medicine until eight hours after administration. It also requires monitoring and should be reassessed after three months so that you have a break from taking it for one week. You should discuss this with your GP. Whether to use tablets or spray is generally the preference of the prescriber.

Jay: Thanks Clare.

Margaret: [Question sent in advance] I was diagnosed in February after MRI & lumbar puncture. I live and work overseas (though returning to UK in January on completion of contract) so really appreciate these 'chat times'. My question is, when I need to pass urine, I am totally unable to 'hold on'. I know this is usual with MS but will it ever improve/deteriorate? Is my spinal cord always under attack? What triggers it? I am fortunate in that I have few other symptoms - just 'funny legs' without mobility problems, trigeminal neuralgia twice.

Clare Lennon: Yes, your problem is very common in MS. Your doctor can refer you to a continence advisor who will carry out the assessment and hopefully also

a bladder ultrasound to determine if your bladder is emptying to completion. If it is, then medication could possibly be prescribed to help with this urgency or she may test your pelvic floor muscles and if weak, may give you exercises to improve these. In many areas you can self refer to a continence advisor. Medication is often very useful. The most commonly used medication is oxybutinin.

Simon - MS Trust: Annette and Dr Kalsi have now joined the room and Clare Lennon has left

Ann: I have mild relapsing remitting MS, diagnosed in 1991. Ditropan causes dryness in the oesophagus. Any other drugs to help frequency problems?

Annette Leach: Can you tell me if you are taking this as a slow release, once daily or if this is more regular?

Ann: Twice a day.

Annette Leach: You may be better off with the slow release version as the side effects are not so evident

Ann: Thanks, I didn't realise there was a slow release version.

Annette Leach: Yes there is. There are also useful tips if you do have problems with a dry mouth, such as using frozen pineapple juice or a drug called Imipramine, but you would need to go to your GP. Have you just started Ditropan?

Ann: No been on it for about five years but only take it when need to. Tried Detrusitol when having longer spell of problems but had bad side effects. It has been mentioned for me to self catheterise, but my problems come and go. What is your opinion on subject?

Annette Leach: Self catheterisation, this would be if you are having problems emptying your bladder. Is this also an issue for you?

Ann: Yes on occasions. Usually I get an infection. I take Amoxycillin but only when need to for the infections.

Annette Leach: Have you been seen by anyone for a full assessment of your continence problems, such as a continence advisor?

Ann: No I haven't. Do you think it good idea even when at moment there are no problems?

Annette Leach: Yes I do as you are taking Ditropan and sometimes this can cause problems with retention of urine. A bladder scan can be useful to check if you have retention of urine. This would be through your continence Service or MS nurse

Ann: That is helpful because when I take Ditropan sometimes have difficulty passing urine and my tummy is firm and tight

Annette Leach: In which case I would advise you see your MS nurse or see your local continence advisor. I hope that is helpful?

Ann: I have had a bladder scan and shown to have retention when having problems but not had advice apart from self-catheterisation, which I am not sure about. Can this cause infection?

Annette Leach: If it has been suggested that you perform self catheterisation then you probably are retaining a certain amount of urine in your bladder. You need to discuss with your local services eg MS Nurse or continence advisor on how to reduce the risk of infections. Initially it may be just technique.

Ann: Thank you very much Annette, you have been very helpful. I shall contact my MS Nurse.

Annette Leach: OK, take care

Bill: I've read about this cannabis spray doing something for bladder problems. Do you have any thoughts on this?

Vinay Kalsi: There are limited studies in cannabis with people with MS. The results of a double blind placebo controlled cross-over trial with cannabis are yet to be analysed.

Chris J: [Question sent in advance] I have slow release oxybutinin 3x 10mg tabs each morning. I must say that it is much better than the basic oxybutinin was.

Annette Leach:

As you say, slow release oxybutinin is more beneficial and you are less likely to have side effects

Chris J: However, I have seen quite a lot written about the cannabis spray and how much it helps bladder problems. Are trials complete, and when is it likely to be available?

Annette Leach: Although most of the trials have been completed, the cannabis spray has not been licensed in the UK. Although the safety of the drug was proven, the data failed to prove its efficacy, although there has been some discussion as to whether the scale used in the trials was sensitive enough. As far as we know, it is being looked at again next year.

Brian: Vinay, my daughter has primary progressive MS and suffers frequently with urinary infections. She has methotrexate. Can you advise what antibiotics are most suitable?

Vinay Kalsi: Hello Brian, how often does your daughter get infections and have they been investigated?

Brian: Probably every couple of months and no there has been no real investigation

Vinay Kalsi: The most suitable antibiotic will be determined by the organism cultured in the urine. Prior to taking prophylactic antibiotics, I feel some investigations need to be carried out. Does your daughter self-catheterise?

Brian: No she doesn't and would be incapable of doing so herself

Vinay Kalsi: Do you know if your daughter has a residual volume having emptied her bladder?

Brian: No idea - neither the GP nor consultant has done anything other than treat

Vinay Kalsi: I feel that a bladder scan to check a residual volume will be helpful. Stagnant urine can be a nidus for infection. Other reasons for urinary infections should be looked at. These include looking what is being cultured, urine for cytology for any abnormal cells, ultrasound of the renal tract in case there is any anatomical abnormality of the renal tract or anything like stones present that may well be a nidus for the infections.

Brian: Presumably we should request that through the GP. In the meantime what antibiotics are most compatible with methotrexate?

Vinay Kalsi: Antibiotic therapy must be tailored according to the organisms grown, and your local microbiology department should be approached in order to get the most suitable answer. This can be done through your GP/Urologist.

Brian: I was wondering about botox

Vinay Kalsi: Botox or rather Botulinum toxin A is being shown to be a very effective second line treatment for people with overactive bladders who have had little success with oral medication. The main drawback so to speak is the risk of having to perform intermittent self catheterisation to fully empty the bladder.

Fiona: How long does botox last for?

Annette Leach: Botox can last for up to 10 months depending on dose

Fiona: Could I get botox at my local hospital?

Vinay Kalsi: If your local hospital has ethical approval for this treatment then yes. But in my experience, it is given in limited centres and as apart of a clinical trial.

Fiona: My local hospital does not do botox. I saw someone privately and they said I would need it every six months

Vinay Kalsi: At the National Hospital for Neurology and Neurosurgery at Queen Square in London, we have an ongoing trial in treating the symptoms of an overactive bladder with botulinum toxin A and we only reinject when the symptoms have returned to pre-BTX days. Average time to reinjection we have found is 10.6 months.

Jonathan: I've just been to an exercise session with Shrewsbury enablement team. I am pooped. It's fatigue that gets me down any tips apart from exercise?

Annette Leach: Exercise can help with building up the stamina in relation to the fatigue but you also need to be sensible about how much you are doing. Have you also looked at your lifestyle and incorporating rests within your day?

Jonathan: Just doing a bit twice a week at present and yes trying to get rests in also

Annette Leach: That is great. If you are still getting very tired, have you looked at other aspects of your day and what you are doing?

Jonathan: I only get tired at the end of the day. Otherwise OK

Annette Leach: It is common to feel more tired at the end of the day with MS. There are fatigue management programmes and it would be helpful to discuss this with your local MS nurse

Jonathan: She is aware of my symptoms

Laura: Hello. I have a question. Does incontinence affect all types of MS?

Annette Leach: It is a common problem encountered with any type of MS. It can vary in severity however.

Jonathan: What's your view on cannabis and its use? I find it helps the pain go

Fiona: Does the cannabis help your bladder, Jonathan?

Jonathan: No better, no worse. So I would say OK

Fiona: I saw on the website that cannabis helps bladder problems. How could I get some?

Vinay Kalsi: The results for the placebo controlled crossover trial are still to be analysed.

Sarah: Hello Dr Kalsi. You and Mr Dasgupta treated my bladder with botox five weeks ago and I was interested in seeing what questions people would be asking this afternoon

Vinay Kalsi: Hello Sarah, how is everything going?

Sarah: Very very very well thanks. I feel I have my dignity back

Vinay Kalsi: That's good. Maybe you could help in giving a patient's view on the treatment and your experience.

Sarah: OK, here goes. I have primary progressive MS and have quietly suffered from an 'unpredictable' bladder for the last five years. The urge incontinence that I experienced severely curtailed my life. I would only go out if I could quite literally be sat next to a bathroom! I am 42 and have a husband and four kids. Wearing pads really knocked my confidence. I took a change of clothes everywhere I went! I was lucky enough to be deemed a suitable candidate for the botox trials at the National. I received this treatment approx five weeks ago and wow! No accidents, to date, no pads, no panics, no humiliation! If anyone is worried about the procedure all I can say is don't be. Dr Kalsi, Mr Dasgupta and Gwen (nurse) treated me with courtesy and sensitivity.

Simon - MS Trust: What was the procedure itself like?

Sarah: The procedure involved a catheter being inserted into my bladder and then a sort of camera being placed in the catheter. Once the sites to be injected were identified, the doses of botox were injected. The entire procedure took about an hour. On a pain scale of 1-10, it was about a 4! Much less painful than having children!

Fiona: How often can you have botox if it last for only 10 months?

Sarah: I believe you can have it done again once it wears off, am I right Dr Kalsi?

Vinay Kalsi: Sarah, many thanks for that wonderful account. I'm sure that this will be of much help to those are logged-in. Fiona, once the botox has worn off, then you will be ready for the next round of injections.

Fiona: So could I have it every year for the next 20 years?

Vinay Kalsi: You must be aware that there is no long term data on the effects of Botulinum toxin A on the bladder. Botox has been successfully used in other areas of the body without any adverse effects, if this is the case with the bladder, I cannot tell you. In theory, there should be no reason for its long-term use.

Fiona: Does it work as well the second time as the first?

Sarah: I have to go now, my children want feeding. Thank you Simon for organising this session. Dr Kalsi, many thanks to you and your team.

Simon - MS Trust: Thank you for your contribution, Sarah.

Vinay Kalsi: From our experience with repeated injections at Queen Square, yes is the answer. Duration of action for 1st and 2nd injections is comparable. We are acquiring more data on 3rd injections.

Fiona: Can I come to Queen Square?

Vinay Kalsi: You are most welcome. Please have your GP/Urologist send a referral to the department of Uro-Neurology. We can then take matters on from there.

Fiona: I have a friend who had something called neuroblock but it only lasted her two months. Is that the same thing as botox?

Vinay Kalsi: Neurobloc is Botulinum toxin B, a different isomer of the Botulinum toxin molecule, and has a shorter duration of action.

Fiona: I also leak when I cough does the botox help that?

Vinay Kalsi: Botox will help with symptoms of an over active bladder eg urgency, frequency etc. Stress incontinence, eg leaking when coughing is an issue of the pelvic floor musculature and botox will not help that. Pelvic floor exercises may well help.

Bill: Are pelvic floor exercises for women only or is it something men can do too? What do they involve?

Vinay Kalsi: Pelvic floor exercises are NOT limited to women. Men can perform them as well and you will be able to get more info from your local continence advisor or physiotherapist.

Bill: Thanks

Vinay Kalsi: No worries Bill

Simon - MS Trust: Alison, do you have a question on bladder problems?

Alison: I don't really have problems with my bladder it is my bowels that cause more problems

Annette Leach: Can you give an idea of the problem?

Alison: It happens once a month, and I just have no sensation to push

Annette Leach: When you say it happens on a monthly basis, can you describe what is happening and are you constipated?

Simon - MS Trust: Hello Maryann

Maryann: I have had three bladder infections in five months. Is this common with MS? I have never had one before

Annette Leach: If you are having problems with infections, it sounds as though you need to be assessed properly. Have you been referred by your GP or have you been seen by a continence advisor?

Maryann: I am scheduled for urodynamics test. Just wondering is there I can do besides pushing water? My GP set up the appointment. I have an appointment with an MS incontinence doctor two weeks later, but this will not be for another month

Annette Leach: OK, that's fine. The other thing that might be helpful to reduce the risk of infection, as a general point, is if you are sexually active to ensure hygiene. Pass urine before and after intercourse and to be aware of hygiene eg washing from front to back around this area will also be helpful. Does this help?

Maryann: No. I am so numb from waist down that sex is really not an issue

Annette Leach: OK, I think that if you are being seeing by the continence advisor in the next month then they will be able to advise when they see you. If you are numb from the waist down are you aware that you need to empty your bladder?

Maryann: Depends upon the day. Sometimes I am, sometimes not

Annette Leach: This may be the reason that your GP has sent you for urodynamics as, if you are not emptying your bladder, then it is often the reason someone is getting recurring bladder infections. Have you ever had a bladder scan to check this out?

Maryann: No what is a bladder scan?

Annette Leach: A bladder scan is a very straightforward procedure that can be done by a trained nurse eg your continence advisor or perhaps MS nurse if trained. It involves scanning across your lower abdomen once you have emptied your bladder. This will pick up any urine left in your bladder which will indicate that your bladder is not emptying properly.

Maryann: Thank you, Annette. Sometimes when I try to void I have severe pains and can't. Is this caused by infection or not emptying my bladder completely?

Annette Leach: It could be both. Have you discussed this with your local MS nurse?

Maryann: No. I will not see the MS clinic nurse until after my appointment.

Annette Leach: It is worth mentioning the problems that you are experiencing to the continence nurse and when you go for urodynamics as this does need to be looked into. Leaving urine in the bladder can ultimately cause problems with the kidneys if there is a lot remaining. There are ways of managing this.

Maryann: My GP thinks I will be taught to self catheterise. Not sure what it means.

Annette Leach: If you are retaining urine, then that is one way of managing it. Intermittent self catheterisation is a procedure that you can be taught. It means passing a fine tube into your bladder and emptying the urine through this tube into the toilet. It is then removed immediately. This procedure can be done several times during the day or once a day depending on the person's problem and severity. Does that help?

Maryann: Won't that increase infections?

Annette Leach: Once you have mastered the technique, you should not have the problem of increased infections as one of the reasons for recurrent infections is because of urine left in the bladder.

Maryann: Thank you, Annette for your help. Thank you MS Trust for this forum. I will read transcript. I'm sure it will be helpful

Annette Leach: OK, take care Maryann

Simon - MS Trust: Hello Veronica. Do you have a question?

Veronica: I have been taking cranberry forte pills - any good?

Vinay Kalsi: Yes, if they have been helping you. What are you taking them for and what dosage?

Veronica: I take them for a leaking bladder. I take 200grms.

Vinay Kalsi: In my experience cranberry tablets 300-400mg twice daily have been used to try and alter the pH of the urine to try and keep infections at bay. I have not come across their usage for leaking bladder. If it helps, well good, but please check the dosage, as they can predispose to the formation of kidney stones.

Veronica: Thanks - bye for now

Simon - MS Trust: Hello Jane. Do you have a question on bladder problems?

Jane: How can I tell if the bladder is not fully emptying? What problems arise if not emptying?.

Annette Leach: The symptoms you might experience are; the feeling of incomplete emptying when finished on the toilet, infrequency or even frequency. You may also have problems with having to get up at night as well as possible urine incontinence. If you do not empty your bladder properly you may eventually have problems with the kidneys, therefore we do suggest that any symptoms are investigated

Jane: They were, 18 months ago. The continence nurse did a scan and on the second visit I was emptying okay. What is done about it? I find catheters scary. Is it painful?

Annette Leach: No they do not hurt. What you need to do is talk to someone locally about what it entails. Whoever teaches you would explain and show you what they look like and how soft they are. There are several types, so if you do not get on with one particular brand, you can try others

Jane: Is it something that once you start doing it you lose the ability to empty, ie do you then have to keep doing it? Or is it perhaps something done during a relapse but then sorts itself out?

Annette Leach: If you are not emptying because your bladder is not able to empty for you, then it will be necessary to do self catheterisation long-term. But if it is due a relapse then you may find it will recover sufficiently enough for you to go back to emptying it normally.

Jane: Thanks for info.

Simon - MS Trust: Hello Liz, do you have a question on bladder problems? The experts online are Annette Leach, an MS nurse, and Vinay Kalsi, a urologist

Liz: I hear a lot about bladder incontinence, but how many suffer from bowel incontinence? Do people just stay at home - or is there a solution?

Annette Leach: The number of people with bowel incontinence is unclear as this is a subject people are not always open about. It seems that about half of people with MS or more can experience bowel problems to a varying degree. It is not always straightforward but you do not need to stay at home. What sort of issues are you experiencing?

Liz: I have attacks of explosive diarrhoea and don't get to the bathroom in time

Annette Leach: How often does this occur?

Liz: It was occurring every day but is now only occasional since I have restricted my diet considerably.

Annette Leach: Yes, some of it you will be able to control with appropriate diet and fluids. Have you ever seen a dietician?

Liz: No. Would you advise this?

Annette Leach: If you are having problems with your bowels, especially explosive diarrhoea, a dietician may be helpful. Do you have problems with the urge to go? Do you find it difficult to hold on as well as the urge?

Liz: Yes. It either comes at the last minute, or comes and stays for a day or two without my being able to empty my bowels

Annette Leach: It sounds as though you need to be fully assessed by your local continence advisor who can examine you and also identify properly whether you have a weak anal sphincter

Liz: It's difficult to hold on, but the continence nurse gave me exercises which have helped a bit

Annette Leach: Pelvic muscle exercises?

Liz: yes

Annette Leach: OK, are you still doing them on a regular basis? And has she gone through diet with you?

Liz: Yes. I do the exercises regularly. The nurse was very helpful - examined me, etc. The diet has really had to be trial and error. I've kept a food diary for over a year now

Annette Leach: Excellent. Do continue to do so. The other thing that would be helpful is to ascertain whether certain foods are causing a problem. Is there anything that is triggering it?

Liz: Quite a lot of foods seem to trigger it.

Annette Leach: Is there anything in your diet that you can omit?

Liz: I have omitted eggs, lettuce, tomatoes, potatoes, dairy, yeast (which includes a lot of things -bread, etc)

Annette Leach: The sort of foods that cause explosive results are things like nuts wholemeal bread seeds.

Liz: I seem to be ok with nuts and seeds, but could they have a very delayed effect?

Jane: Liz, a dietician I saw was also interested in how I digested food as well as what I was eating and that has helped

Liz: How did the dietician test how you digested food?

Jane: I can't explain that easily. Questions and some tests, and monitoring the changes made

Annette Leach: Do you have your bowels open regularly and is it a hard stool?

Liz: My bowels open fairly regularly and are quite soft.

Annette Leach: If they are soft then it might be worth discussing with the continence advisor. There are drugs that may help such as Imodium. As I do not have your history it is difficult to advise specifically

Liz: Is it safe to keep using Imodium?

Annette Leach: Have you used it before? Normally you would use it as and when

Liz: I used to use Imodium every time I went out. Now I'm trying to give it up, but going out's nerve wracking.

Annette Leach: In Ms you can get two problems with you bowels - either constipation or what we call a slow transit bowel, which means you go but it may be several days before you have a result

Jay: I use liquid Imodium for my unreliable bowel - a small dose as and when, it's very helpful

Annette Leach: Is there a reason you are trying to give up the Imodium?

Liz: It has a very long lasting effect. I can be constipated for a week or two afterwards

Annette Leach: You may be better off with the liquid version as then you can use it in smaller amounts

Liz: I hadn't come across that. Thank you, I'll look out for it.

Jay: Liz, you can buy liquid Imodium over the counter or your GP can prescribe. It's not expensive.

Liz: I'll buy the liquid type next time!

Jane: Simon, is today's chat room mainly for bladder problems? If so could a future one be about bowel problems especially if so many people with MS experience problems?

Simon - MS Trust: I think you are right. It is a topic that has cropped up throughout the day and could well make for a chatroom in its own right.

Linda: I need help with my bladder problems

Simon - MS Trust: Is there a specific problem?

Linda: urgency is the biggest problem and not holding on when I need to go

Annette Leach: Do you have difficulty with stress incontinence as well eg leaking on coughing etc

Linda: Yes

Annette Leach: Stress incontinence is not related to the MS . It normally develops from weakened muscles at certain times of people's lives, such as following pregnancy, middle age due to change in hormones and later on again in life. With regards to the urge, it is useful to be seen either by you local MS nurse or by the local continence service to identify what exactly is going on.

Linda: Is there any drug or medication to help?

Annette Leach: There are some drugs that might help but you need to be assessed by your MS nurse first to determine exactly what is going on

Linda: is there any food/drink which I should avoid?

Annette Leach: Fizzy drinks are best avoided as well as anything with seeds or nuts, but you need to be assessed by a dietician, through your GP, to get the specific advice for you.

Simon - MS Trust: Hello Geoff

Geoff: Has anybody come across any alternative therapies for bladder problems?

Annette Leach: What sort of problems are you experiencing?

Geoff: Frequent urge to go but also a difficulty in getting started once there

Annette Leach: Acupuncture has been shown to be effective in some cases as an alternative to medicines but there are others. The MS Therapy Centres can be a good source of alternative therapies. You can obtain the information on your local centre at www.ms-selfhelp.org

Simon - MS Trust: Hello Kathy, welcome to the chatroom on bladder problems

Kathy: Has anyone any experience of using a new drug, solifenacin (Vesicare) and has it helped? What are the side effects from it?

Annette Leach: I have not have experience with the use of Vesicare but it is used for people who have problems with urge , frequency etc. The usual dose is 5mg daily but this can be increased to 10mg daily. It needs to be taken with liquids and swallowed whole. The side effects are similar to other drugs for overactive bladder eg can sometimes cause blurred vision, constipation, etc

Kathy: I have been recommended Vesicare by the National Hospital in London, as a new drug, only recently available in the UK. I have found that other drugs do not help me very much

Georgia: My problem is frequency. That's interesting. I will mention it to my MS nurse

Annette Leach: What other drugs have you tried?

Kathy: Have tried oxybutynin XL and detrusitol XL . The latter made me sick and the first helped only a little.

Annette Leach: There is another one called regurin for your information

Kathy: Thanks for your help.

Georgia: How frequent is frequent enough warrant drugs?

Annette Leach: Ideally you need to do a record for either the MS nurse or the local continence advisor in order to establish what is the extent of the problem. It will also be useful to know not only what you are passing (urine wise) but also what you are drinking. So it is not only the frequency of the problem, there are other factors that need to be considered. Frequency may also be due to a urine infection and that would need to be checked by your local GP

Georgia: I understand. Thank you for your advice. I will look in to all areas closely.

Annette Leach: No problems I hope it was helpful. Take care

Jay: I was advised to take desmopressin when I'm going on a flight but how do you cut down on liquids and drink enough on the flight?

Annette Leach: It depends on the length of the flight but usually you would have your last drink an hour before you take it and then eight hours after taking it

Simon - MS Trust: The room will be closing in a few minutes if anyone has a final question

Jay: Thanks. How do you manage to sit there all day!

Annette Leach: I have a pressure relief cushion!! :-)

Simon - MS Trust: OK, I think we'll end it there. Thank you to everyone for their questions and contributions. Many thanks too to Annette and earlier in the day, to Kim, Clare and Vinay for acting as experts