



Bowel problems

Chatroom

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26 April 2006 – 10am to 7pm:

The experts:

- **Annette Leech** – *MS specialist nurse (10am – 3pm)*
- **Vinay Kalsi** – *registrar in Uro-Neurology (10am – 3pm)*
- **Sue Woodward** – *nursing lecturer (3pm – 7pm)*

This chatroom is an open forum and so the views expressed by participants are not necessarily those of the MS Trust. For further information on topics raised, please contact the Information team at info@mstrust.org.uk

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Simon - MS Trust: Welcome to the chatroom. Annette and Vinay are online and ready to answer your questions.

Ron: Does bladder urgency and frequency usually lead to bowel problems in time?

Annette Leach - MS Nurse: No, not necessarily. They are completely separate issues

Ron: I had bladder urgency/frequency until I started on LDN six months ago. There was a marked improvement overnight from day one and I have never had a problem since. I was curious as to whether bladder problems may lead to bowel problems in future, but I think you have pretty much covered that, thank you

Annette Leach - MS Nurse: You're welcome, Ron. Any other queries come back to us

Ron: Just a question/enquiry. Are bowel problems because of lack of muscle control and possible lack of communication from nerves?

Annette Leach - MS Nurse: Yes you are correct. It is due to interference in the messages getting through to both the nerves that deal with sensation and the the nerves that directly go to the muscles of the bowel.

Natasha: Hello, thank you for covering this topic and hopefully you can help I have lost alot of feeling from my waist down and am finding going to the toilet difficult. I am only going at best every five to six days and can be as long as two weeks. I feel that my bowel is full but I cannot move it. It seems to make all of my symptoms that bit worse. I have tried laxatives but don't feel that they work but I don't think that is the problem - my muscles seem to tense and not to relax. Any suggestions?

Annette Leach - MS Nurse: It is often the case that when you experience reduced sensation, it is more difficult to know when you have a full bowel. There are ways in which this can be addressed. You say you have tried medication - which ones?

Natasha: Senokot and similar from Boots

Annette Leach - MS Nurse: It sounds as though you have a problem with slowing of the bowel (common in MS) What you are eating can make a difference. Do you take alot of fibre in your diet and drink adequately?

Natasha: I probably don't drink enough actually. I do have a good diet - fruit and veg every day. I eat pasta and rice regularly.

Annette Leach - MS Nurse: You need to drink about two litres of fluid a day depending on your weight (the continence advisor or MS nurse should be able to tell you). If your bowel is slow, having too much bulky fibre, eg bran, will not help. But the foods you have said seem to be ok. Other things that can help the bowel are exercise and the actual sitting technique. Abdominal massage can also help. This is information you should be able to get form the continence Advisor

Natasha: Thank you for the advice.

JohnM: I have secondary progressive MS and have for many years been experiencing bowel problems - attributed to MS. I have just been diagnosed with Coeliacs Disease. What is the prognosis? I am seeing the dietician next week.

Annette Leach - MS Nurse: Coeliacs disease this is not really my remit, but it is something that can be managed with the appropriate diet

Vinay Kalsi - Registrar in Uro-Neurology: John, I agree with Annette with regard to the coeliacs. There are many gluten free products that are now widely available to help regulate your diet and symptoms of the coeliacs. The dietician will be able to advise you. What bowel problems have you been experiencing with MS?

JohnM: Bloating after meals, with frequent bouts of diarrhoea followed by constipation. It seems worse when I eat wheat/gluten based foods. But when I try to eat five a day fruit and veg, I get the runs.

Vinay Kalsi - Registrar in Uro-Neurology: John these symptoms may get better with a gluten free diet - your dietician will be the best person to advise on this. It may be difficult to assess what bowel problems you are having with the MS as these symptoms may be masked by the coeliacs

JohnM: Many thanks for your input.

Caroline: My doctors think I may have IBS (irritable bowel syndrome) but before this, they looked at my ovaries, which were ok. But I have none of the usual signs. Busopan is no help but I have had pain in my left lower side for the last six months. It's getting worse and now I am starting to lose the plot.

Vinay Kalsi - Registrar in Uro-Neurology: Is the pain on the left lower side the problem?

Caroline: Yes, it is

Annette Leach - MS Nurse: If you are experiencing pain, has this been thoroughly investigated by a Specialist Consultant and have you had a abdominal x-ray? There are several things that might be causing the pain, not necessarily linked to MS

Keith: I care for my wife, who is totally immobile except for the ability sometimes to stand momentarily to transfer from wheelchair to armchair. At other times we use a ceiling or mobile hoist. She has a suprapubic catheter. She eats a fairly regular diet with cereal and fruit. All through her healthy life, her bowel movements had been consistent. First thing in the morning every day and that's it. However, as her MS has progressed, it has become a big problem. She takes senna tablets prescribed by her GP. Two every night. Sometimes they work and she is very loose with occasional incontinence, while at other times she just cannot make a movement. In those cases a suppository can do the trick, but at other times it does not. Is an enema appropriate? If so how can I go about it to help her as she relies entirely on my practical attention (if you see what I mean!)

Annette Leach - MS Nurse: Bowels can change with disease progression, due to various reasons, for example lack of mobility, reduced sensation of the bowel and muscle weakness of the bowel. In which case the bowel management regime then needs to change. Have you spoken to your District Nurse about these issues? The main things you need to consider are - adequate diet and fluid intake; sometimes abdominal massage prior to getting up; regular meals; laxatives such as Movicol may be helpful but you need an individualised plan as everyone is different.

Vinay Kalsi - Registrar in Uro-Neurology: If constipation is the problem, it may be because of slow transit of material through the bowel. If this is the case, then your wife will benefit from some form of stool softeners by mouth and rectal stimulants from below such as suppositories to aid emptying. The incontinence may be due to liquid stool coming over the constipation. Foods with a great deal of fibre such as cereal may actually make the situation worse as it can bulk up the stool and make it go through the bowel slower. Please make sure your wife's fluid intake is good

Keith: Thanks for your suggestions and advice but what about enemas.

Vinay Kalsi - Registrar in Uro-Neurology: Enemas may be a good idea. If your wife gets any sensation of the rectum filling, ie wanting to pass motion, the a microlax enema may be useful in stimulating the rectum to contract.

Annette Leach - MS Nurse: An enema may be appropriate but you need to discuss this with the district nurse with regards to which one is best and obviously who is going to do it.

Keith: Many thanks.

Christine: I was diagnosed with irritable bowel and advised to eat more fibre etc., but this just makes it worse. Everytime I eat it seems to make my rectum feel loaded straight away but I can't pass anything when I try. It is very uncomfortable and puts me off eating at work as then I get wind. I don't open my bowels at all unless I use a suppository. Is this the slow bowel you are referring to do you think?

Vinay Kalsi - Registrar in Uro-Neurology: With MS, the transit time of material passing through the bowel may become slower. The bowel absorbs fluid from the faecal matter. If it is there for a while it will lead to constipation. With slow transit, fibre may make matters worse by bulking up the stool. Fibre will also cause flatulence. A balance needs to be struck and you need to ensure your fluid intake is adequate

Annette Leach - MS Nurse: You say you feel bloated after eating. There may be foods that are causing more problems than others. Have you seen a dietician to go through what would be appropriate?

Christine: Thanks. Sometimes even using a suppository, the faecal matter seems to be such a huge mass that it won't come out. I use Movicol but that just makes it sloppy. My main difficulty is actually passing the motion which is in my rectum but doesn't want to leave! I will try cutting out my breakfast cereal and such like and drinking more - although I do drink a lot (not alcohol hee hee!) already.

Vinay Kalsi - Registrar in Uro-Neurology: Movicol is not a stool softener. Have you tried anything like docusate or lactulose?

Christine: I tried Lactulose years ago - maybe I should try again. I thought Movicol was a stool softener - what does it do then?

Vinay Kalsi - Registrar in Uro-Neurology: Movicol is an osmotic laxative. It's main function is to lubricate the stool by drawing fluid from the bowel

Clive: If it's any help - I've found probiotics useful in keeping regular. You can get them in capsules if you don't fancy a yogurt drink (as advertised extensively on television). Glycerol suppositories and senna-based things however cause irritation (to me anyway).

L - community OT: We have a client who is posing considerable issues in relation to his bowel management regime. The client refuses enemas given by the nurses and, as a result is producing large and continuous amounts of black fluid . The carers involved are finding him daily requiring 'top to toe' cleaning and, as he is a heavy gentleman, this involves three carers to support him so he can be washed on the bed. We are asking for medical intervention as regards the reason for the black fluid but, even prior to this, the management following an enema dose was very difficult as there were frequent accidents before he could be hoisted on to the commode or toilet. Have you any recommendations as to how this could be more easily dealt with? The gentleman is in a purpose built flat, uses an electric wheelchair and has a ceiling track hoist. His cooperation is limited. We feel strongly that his dignity is severely compromised but are not sure where we go from here. The man is very reluctant to consider assessment or long-term care at the moment.

Annette Leach - MS Nurse: People with MS with high disability often find it difficult to deal with their changing disability and often will try to keep in control of anything as much as possible, including personal issues. Psychologically, he may find it difficult adjusting to his personal dysfunctions and this may well need to be addressed first. Obviously, the black fluid will need to be investigated.

Vinay Kalsi - Registrar in Uro-Neurology: Black fluid does not sound good. Has your client been seen by a gastroenterologist or colorectal surgeon? If not I think it will be a reasonable thing to do

Annette Leach - MS Nurse: I think that the team, eg carers, district nurse and yourself, need to meet with the person with MS and explain the issues that you are experiencing and find out why he is acting as he is, explain that his quality of life would be much better if he would consider changing the current regime. He needs to be the one looking at the situation. Are there issues with cognition, as this may have an impact on how he manages as well?

Linda: I have primary progressive MS and the usual problems of bladder urgency. I find that these days it is nothing unusual for me to go for a week (or sometimes more) without a bowel movement. I eat plenty of fruit and veg as I am a vegetarian, also Fybogel once a day. I can feel that I desperately need a bowel movement, but as soon as I sit on the loo the urge goes. A suppository will eventually get things moving, but I am worried about using them too often.

Annette Leach - MS Nurse: It sounds as though you have a sluggish bowel. In which case too much bulky fibre will make the situation worse. It may be worth discussing with your GP about stopping the Fybogel and using more of a stimulant such as Bisocodyl (tablet or suppository). Also you need to consider if you are taking sufficient fluids and exercise. Also, spending about ten minutes on the toilet after meals and sitting leaning forward will help. The best time to have your bowels open is in the morning as this is when the strongest muscle movement of the bowel will be.

Linda: Thank you, I do try to keep up my fluids, but exercise is difficult as the slightest thing reduces me to an exhausted heap! I can still totter as far as the loo with the help of a trolley, but that is the extent of my exercise.

Vinay Kalsi - Registrar in Uro-Neurology: I would not worry about using the suppositories too often. Their function is to stimulate the rectum to contract. I would also suggest you try a stool softener instead of the Fybogel. Please make sure that your fluid intake is satisfactory. I know that this may be an issue with your bladder problems

Linda: Is it ok to use the suppositories as often as, say, every other day?

Vinay Kalsi - Registrar in Uro-Neurology: Yes, as necessary

Christine: I use a suppository every day, otherwise I feel very uncomfortable having the feeling of stool in the rectum all day. I expect this shouldn't be done but I can't find any other way. I haven't opened my bowels unaided by a suppository for years except once when I had a bout of D&V, (diarrhoea and vomiting) which I have to say was quite nice being able to empty my bowel naturally.

Annette Leach - MS Nurse: Christine, if you find using a suppository the most effective way of managing you bowels then that is fine. I am assuming that it is a glycerol one? If you are using glycerol suppositories they are not a problem even if you use them on a regular basis. Some of the other stimulants can be, but glycerol is safe so long as you have been taught how to use them properly. However there are other ways which you might like to consider: ensuring adequate fiber in diet and fluids, abdominal massage and sitting technique is important when you actually have your bowels open as well

Christine: Yes, I do use Glycerol ones. Thanks for the reassurance as I often worry that I am doing the wrong thing.

Linda: I have tried glycerol, but I find them too rubbery, and I have had fun getting them too wet and shooting them across the bathroom!

Annette Leach - MS Nurse: What are you using at the moment?

Linda: Anusol

Annette Leach - MS Nurse: Anusol is normally used for haemorrhoids. Has this been prescribed by your GP?

Christine: So for clarification - is the reason that when I eat I get the immediate feeling of needing to empty my bowel, because of slowed transit of fibre, so I should ignore the advice of my GP to eat more fibre?

Vinay Kalsi - Registrar in Uro-Neurology: With the normal physiology of the bowel, when we eat we stimulate the release of certain hormones that promote movement of the bowel. This is why some people get the sensation of needing to go to the loo when they have eaten and it is not necessarily anything to do with the fibre

Annette Leach - MS Nurse: It is important to eat the right sort of fibre. Have you ever spoken to a dietician?

Christine: I have never spoken to a Dietitian - I should ask to be referred then. I work in a hospital and my department is right next to the Dietitians, but I guess its not the done thing just to approach them without a referral.

Annette Leach - MS Nurse: It would be worth talking to your GP about seeing a dietician. That is the best way to be referred.

Christine: Thanks very much for all your advice, it has been helpful.

Kate: Please could you tell me what an anal plug is, what it is used for and how it is used? A continence advisor mentioned it a couple of years ago when I was having minor problems.

Annette Leach - MS Nurse: An anal plug is a very soft plug that can be fitted into the rectum once you have had your bowels opened. They reduce the risk of soiling during the day. They come in three sizes.

Vinay Kalsi - Registrar in Uro-Neurology: Anal plugs were developed to help people with faecal incontinence. It is designed to be worn inside the rectum to plug the entrance to the anus from the inside. The plug comes wrapped in a water-soluble film, so that it is easy to insert. The film dissolves once the plug is in the rectum, and the plug opens into a cup shape and has a string for removal.

Kate: Are anal plugs difficult to insert and remove? I have problems with my hands.

Annette Leach - MS Nurse: Yes, the anal plugs can be a bit fiddly to get them in the correct position in order for them to work effectively.

Vinay Kalsi - Registrar in Uro-Neurology: I think that if you see your continence advisor, he/she will be able to take you through the insertion and removal of the plugs and they may be able to suggest positions you need to be in to put the plug in easily given the problems with your hands.

Kate: Thanks. Seems I'll need to talk with the continence advisor sometime. Things not too bad at present.

Diane: Hi, I have relapsing/remitting MS and apart from lots of water and fresh fruit and veg what are the best foods to eat to deal with constipation? Also I am on tegretol retard for neuralgia. Will this interfere with bowel movements?

Vinay Kalsi - Registrar in Uro-Neurology: Some people find that 'healthy-seeds' such as linseed may help. Green apples / prune / apricots may also help. Ideally you need to ensure that your fluid intake is good and you are not taking excessive fibre that may slow down the transit even more

Annette Leach - MS Nurse: If you are eating fresh fruit and veg then that's fine, as well as fluid intake that is adequate for your weight. Other things can help, such as Weetabix, but avoiding very bulky fibres such as bran. Exercise is also important

Diane: I weigh about 12 stone and I'm 5ft 7. How much water should I be drinking? Exercise is difficult as the relapse I'm in at the moment has taken my legs away and my energy supplies! Will the tegretol have a bad effect? I am also taking Movicol and I am on Rebif three times a week.

Annette Leach - MS Nurse: On average you should be taking about 9-10 mugs of fluid a day, but the continence nurse may well be more specific - this is only a guide. Tegretol should not be a problem. If exercise is a problem then you can do abdominal massage. This technique does need to be shown as there is a specific direction to perform it

Vinay Kalsi - Registrar in Uro-Neurology: Diane looking at the BNF (British National Formulary), it says some of the potential side-effects of tegretol are constipation or diarrhoea - but this goes for most drugs. Tegretol may cause some bowel upset. The general consensus is that fluid intake should be 1.5-2 litres per day

Diane: Thank you so much you have been really helpful.

Julia: I have had progressively worse problems with my bladder and gut. I do not know when I need to go so go every few hours. My bladder holds 450 mls before I get a sensation that I am heating up and have realised that if I go to the toilet this sensation goes away. Regarding my bowels I do all the right things but have found that sitting with my legs raised to assist results in lower back pain and episodes of severe pins and needles in my feet and lower legs. To try and get around this I interlink my fingers and hold my hands against my lower abdomen as I try to pass a motion and this seems to help.

However, I need to take three Movicol a day and cyclazine tds to stop me becoming nauseated and vomiting. My abdomen frequently becomes distended and rigid like a pregnant woman in the middle of a contraction during labour, but I have no pain. My stomach at these times can make no noise and at others it is very noisy. No one is explaining to me what is happening and I feel that one day I might need surgery. This concerns me because I am very weak and feel as though my body would not be able to cope with this extra stress. I also have problems breathing, short of breath easily, same after a meal and have been told I have chronic lung disease although I have never smoked or suffered from asthma. Can you explain what is going on and give me some advice please?

Vinay Kalsi - Registrar in Uro-Neurology: It is difficult to explain what is going on in such a forum. It sounds like you have a number of issues which need to be addressed. I would therefore suggest you get referred to whoever is looking after your MS for assessment so they can send you to specialist physicians to deal with the various problems. I feel you need a good overall assessment before suggesting any form of treatment.

Kate: Can I comment on a couple of bits of advice being given? I found drinking much more water than I used to and cutting out tea and coffee had a beneficial effect. The extra water was difficult to start with but now that is my norm and is okay.

Also not eating fibre in a dryish form helps. So I soak dried fruits (compote is good), and make my own museli mix with oats, sultanas and pumkin and sunflower seeds (which I put through the food processor first). This I soak overnight and then cook as for porridge. Use an electric steamer so no extra washing up.

Annette Leach - MS Nurse: It sounds as though you are doing all the right things at the moment and using energy conservation ideas as well

Chris: I use intermittent catheterisation. My wife complains the toilet always smells of urine and accuses me of 'missing' etc. I think the length of time urine in the bladder or something similar causes strong smell. Any ideas?

Vinay Kalsi - Registrar in Uro-Neurology: Chris the strong smell may be due to you not drinking enough and the urine getting concentrated. The other thing to check for would be a urinary tract infection. Send a sample to your GP. If you feel that urine is in the bladder too long you may need to catheterise more often. This will depend on your residual volume of urine on catheterisation. If you have a continence advisor they will be able to check your technique, see if you are catheterising enough and possibly suggest newer products that may help

Chris: What are newer products? I use water lubricated catheters, find them convenient. And would there not be other symptoms (temperature, etc) with a UTI long-term?

Vinay Kalsi - Registrar in Uro-Neurology: If you are happy with what you are using - well and good. Newer products are always coming onto the market and continence advisors are generally very well informed and can suggest appropriate ones. With UTIs (urinary tract infections), you may well get a temperature, pain on passing urine, even blood in urine if the infection is quite established. Some patients with MS do get problematic infections which are difficult to eradicate and may not give many symptoms. Smelly urine may be the only sign. It is therefore important to ensure a good fluid intake and have your urine tested.

Chris: Is it bad to be using Senna and other laxatives as well as suppositories and enemas and having two motions a week? Is there a limit to how long it can go on, and some sort of surgery required in general?

Annette Leach - MS Nurse: What are the other laxatives that you are using at the moment?

Chris: I use five or six Senna a time and two Bisacodyl tablets, and one or two days later sit on toilet and usually need two or three suppositories's and an enema or two.

Annette Leach - MS Nurse: Are you taking any medication? Also diet and adequate fluid intake are important

Chris: I take Oxybutinin. Desmoltabs and Imipramine at night to reduce nocturia. Vitamins. Fluid and diet can always be better, but I feel OK.

Dawn: My tongue is really black. I suffer from IBS (irritable bowel syndrome) are the two connected?

Annette Leach - MS Nurse: Are you drinking enough? Are there other issues that you have not mentioned?

Dawn: I do drink enough. I do have cold sores at the moment and I have just had a hysterectomy. I also haven't got much energy. My black tongue is worrying me more than anything else!

Annette Leach - MS Nurse: You can get a furring of the tongue if you are constipated. Is there any medication or drinks that might also be causing this?

Dawn: I'm not constipated but my IBS has caused bloating and wind recently. I'm on oestrogen patches and take St Johns wort. I drink about a pint of Diet Coke a day as well as water and squash.

Annette Leach - MS Nurse: Fizzy drinks can also cause bloatedness and wind. It might be worth considering changing the Coke for a better alternative that is a still drink. Water is the very good at keeping you rehydrated.

Vinay Kalsi - Registrar in Uro-Neurology: Dawn, have you seen your GP about this?

Dawn: No I haven't. Do you suggest that I should?

Vinay Kalsi - Registrar in Uro-Neurology: I suggest you see your GP. You have recently been through an operation, you have lack of energy and cold sores which may suggest that your immune system may have taken a knock. If you have been on antibiotics whilst you had the operation it may predispose you to having some infections of the tongue/throat eg thrush. I cannot explain the black tongue but I would see a doctor

Dawn: I will, thank you so much for your help.

B: I have seen several clients recently who have complained of excessive bloating, especially worse towards the end of the day. Could this be related to food, position or symptom of IBS/MS?

Vinay Kalsi - Registrar in Uro-Neurology: B are these MS clients?

B: Yes, they are. One has recently become chairbound which is why I asked about positioning.

Annette Leach - MS Nurse: Bloating can be due to various reasons, such as food and constipation, as well as IBS. It may be due to medication as some of

the laxatives can cause bloatedness.
A full assessment would need to be done.

Vinay Kalsi - Registrar in Uro-Neurology: I agree with Annette's comments. An assessment will be necessary. With positioning, I think that a reduction in movement/exercise may play a role in slowing down the gut and causing bloating and constipation.

B: Thank you. I have ruled out constipation. Drinking well in both cases, enjoying diet with fibre. On waking there is no bloatedness but builds up over the day. I suggested peppermint water but couldn't think of anything else!

Annette Leach - MS Nurse: What types of fluids are your client's drinking, as this can have an impact on feeling bloated as well?

B: Tea, coffee, water and squash

Annette Leach - MS Nurse: That's fine. Coffee is a stimulant and may cause some bowel activity.

Brenda: I am 62 and have 'benign' MS. My problem is seepage - not caused by constipation but a continuation after a movement that can last all day, although not every day. Is there any advice on how to cope as lack of confidence curtails my activities? I am haunted by the old joke of sniffing a baby and declaring it needs changing!

Vinay Kalsi - Registrar in Uro-Neurology: This is not a common symptom and I feel it needs further investigation. Have you seen a colo-rectal surgeon?

Annette Leach - MS Nurse: Obviously it is important to enjoy your activities, so first I would like to ask if you have ever had this properly investigated? It may not necessarily be due to MS. It depends on how long you have experienced it as well. There may be problems directly due to anal muscles. You need to talk to your GP for a referral or to see the continence advisor for an assessment. There are exercises that you can do but again this needs to be assessed by the relevant specialist or continence advisor to see if this is practical. There are also anal plugs that can help in reducing the soiling but again you will need to the continence advisor for advice. Sometimes it may be due to incomplete emptying of the bowel so it is better to seek professional advice to appropriate management. I hope this is helpful

Eilidh: How helpful or safe would colonic irrigation be if used with the MS bowel?

Vinay Kalsi - Registrar in Uro-Neurology: Eilidh colonic irrigation is not a practice we advocate

Annette Leach - MS Nurse: This is something that I have not come across regularly, although I do know of one client who was investigating this. I will refer this to the MS Trust Team to research for you. I hope this is helpful

Simon – MS Trust: I have not been able to find any published information on colonic irrigation and MS and there seem to be no known benefits. In the general population, some people report feeling revitalised for a while after therapy, but the claims that colonic irrigation has a 'detoxifying' effect are possibly more spurious.

Possible problems that have been associated with colonic irrigation involve infection from the equipment and damage to the colon or worsening of haemorrhoids. A reputable therapist should be able to explain the steps taken to avoid these problems. People with existing diseases of the intestine need to discuss these before therapy.

Colonic irrigation is not a treatment for bowel problems in MS and the therapy will not address the underlying cause of symptoms. These problems should be properly assessed by a continence advisor and appropriate management techniques considered.

M: Why is it that taking things like Movicol or Fybogel for constipation takes at least three days to work? I had a barium swallow test recently and that again took three days to get through my system. Is this MS related?

Vinay Kalsi - Registrar in Uro-Neurology: Fybogel is a bulking agent. It is ispaghula husk based and used to bulk up the stool. Movicol is an osmotic laxative - it draws water out of the bowel to aid lubrication of the stool. MS can cause slow transit of bowel material and therefore it can take longer for material to get through your system.

Annette Leach - MS Nurse: It sounds as though you are describing a sluggish bowel (slow transit bowel) which can be as a result of the MS causing muscle weakness of the bowel wall. In which case it is important to ensure you do not take too much bulky fibre such as bran. Fybogel may also cause problems if you do not drink adequately. Movicol helps to reduce constipation by drawing fluid into the bowel, but if you have a slow moving bowel it may be useful to use a stimulant such as bisacodyl as well. Everyone is different and it you may find that you need to trial and error with the laxatives. You may not necessarily need to take the stimulant every day. If you need further information, it might be worth talking to your GP and seeing a dietician to discuss appropriate fibre

Muriel: Are colostomies ever done on MS people with severe bowel problems?

Vinay Kalsi - Registrar in Uro-Neurology: Yes, but usually as a last resort

Muriel: I am a retired GP. My main problem is inability to expel faeces from the bowel. I take one Movicol and use one microlax micro enema daily. This only works fairly well

Annette Leach - MS Nurse: Would an oral stimulant be worth trying? For instance, bisacodyl instead of the enema?

Muriel: I still seem to need enema to get started, no matter how long I sit. Also I sometimes need manual help (from myself)

Annette Leach - MS Nurse: Have you got a bowel routine? Do you go regularly every day at a set time?

Muriel: Yes, every morning

Vinay Kalsi - Registrar in Uro-Neurology: With nerve loss to the rectum as a result of the MS, initiating a rectal contraction becomes difficult. Rectal contractions will initiate emptying. Stimulation of the rectum, be it digital or with the enema will start off a contraction, which will then get the rectum contracting and emptying.

Muriel: Any idea what percent of MS people would have a colostomy performed

Sue Woodward - Nursing Lecturer: Sorry Muriel, I don't know how many people with MS end up with colostomies. I do know that about 70% or so have bowel problems though.

Muriel: Many thanks for all your helpful info.

Liz: I suffer from occasional diarrhoea and faecal incontinence (though constant upset stomach). Are there any dangers long-term (particularly for the central nervous system) from taking the occasional loperamide?

Vinay Kalsi - Registrar in Uro-Neurology: The occasional use of loperamide is ok. If you find you are using loperamide on a regular basis long-term, I would suggest you have your symptoms investigated by a specialist

Liz: What damage could you expect from loperamide? My GP prefers me to take three mebeverine a day (which gives me terrible stomach cramps) to taking one loperamide (which makes my stomach feel a lot better) every two or three weeks when I go visiting relatives.

Vinay Kalsi - Registrar in Uro-Neurology: If the mebeverine is giving you stomach cramps one would wonder if this is the right thing to do - why are you on this? Loperamide should not be given if diarrhoea is as a result of any form of infective diarrhoea or as a result of bowel obstruction. If this is ruled out, this can be done by your doctor, then its use is quite safe.

Liz: I soon stopped taking the mebeverine, and I suspect that my GP's insistence that I take this drug every day has something to do with payments from the drug company. Surely it can't be less damaging than the occasional loperamide! (I have undergone all the investigation I'm prepared to undergo at the moment. It revealed nothing more than dysmotility). I'd expect the over the counter drug to be less damaging than the prescription only mebeverine.

Vinay Kalsi - Registrar in Uro-Neurology: Any drug, be it over the counter or prescription, still has the same active ingredient and can be equally 'damaging'. The instructions for administration should be noted and adhered to.

Chris: What do specialists think of routine of four or five Senna and two Bisacodyl twice a week with enemas and suppositories too? May its use fade or cause problems?

Annette Leach - MS Nurse: How long have you been having this regime of senna and bisacodyl?

Chris: On and off for 18 months or more

Annette Leach - MS Nurse: Senna if used on a long-term basis will reduce the efficiency of the bowel as it coats the lining of the bowel. Bisacodyl is not so much of a problem but it may be worth considering other options like abdominal massage, exercise and as well as appropriate fluids and diet. Enemas can be useful or suppositories if you need to stimulate the bowel in order to gain an evacuation of stool.

Chris: Thanks. I hadn't heard that about Senna. Sounds serious. How about regular use of suppositories and enemas?

Annette Leach - MS Nurse: Suppositories such as glycerol and bisacodyl are fine. Enemas - it depends on which ones.

Chris: The enemas I have are smaller Bandi Enemas and larger Fleet ones. My 'GP' type of doctor said recent data showed long-term use is as safe as suppositories.

Annette Leach - MS Nurse: Those enemas are fine phosphate enemas, which, on a regular basis, would not be recommended

Chris: Are there other types?

Annette Leach - MS Nurse: The micro enemas are ok. There is some phosphate in them. There are others such as the micralax which is free of phosphate. The large phosphate enema (Fletchers large bag) is the one not recommended as it can cause problems with ulceration of the rectum. The macralax is one that I would recommend and you can use it as necessary.

Chris: What are probiotics and where do you get them? Can baclofen add to or worsen constipation?

Vinay Kalsi - Registrar in Uro-Neurology: Probiotics are foods that contain live bacterial cultures, which are there to maintain the balance of the naturally occurring bacteria in your gut. Baclofen according to the BNF (British National Formulary) can cause gastro-intestinal upset but it does not specify what.

Kate: Annette, could you tell us about the sitting technique on the toilet? I have not heard of this before.

Annette Leach - MS Nurse: When sitting on the toilet, it is more effective to lean forward with your knees raised, slightly brought up towards your abdomen. If a person is too short on the toilet, a step is useful in order to maintain this position. The natural position to have the bowels open is actually squatting but obviously not appropriate in this day and age, so this is the next best position on the toilet.

Marcus: Good afternoon. I am male (50), had relapsing/remitting MS diagnosed in 1999. Constipation is an on-going annoyance. I have been taking baclofen (10mg) twice a day and Gabapentin (600mg) once a day for most of that time. GP gave Movicol for constipation which usually works when I take it. I am not very comfortable with taking tablets which probably explains why I still have eight sachets of a 30 sachet box, prescribed 16/07/04. When it does work, I have to be very close to a toilet - no argument. I have watched my diet and fluid intake, which does work temporarily but not long lasting. The Movicol instructions advise on the amount to take and the length of consumption. By coincidence, I took one sachet today (having forgotten at the time of this live chatroom). My query, (which isn't mentioned on the instructions for the Movicol) is when is the best time of day to take Movicol. Reason for asking is that I had assumed that I should be taking the medicine either with or after food. This has worked now and again in the past but today, for some reason, I took the Movicol first thing in the morning before any food or tea etc. So far, things have moved on three occasions till now and I feel in control again of my system. Is it best to take Movicol first thing before anything else or has the success just been coincidental?

Annette Leach - MS Nurse: Movicol can be taken am or pm. It can be taken three times a day. It normally takes approximately six hours to take effect, so I usually suggest taking it initially at night. If you are finding that you are needing to be close to the toilet, I wonder if you are taking too much. I suggest half a sachet to start with and then gradually increasing it if no effect. Once having had your bowels open, stop it and then restart if you find that by the third day you have not been.

Marcus: Thank you for your advice . I have found the information mentioned in this live chat room to be very helpful.

Nigel:I have recently requested my MS Nurse to recommend me to the continence specialist. I now realise that bladder problems I was experiencing years ago, like other problems, were all part of as at the time undiagnosed MS. I now have other problems and joked to the specialist when arranging an appointment about the need for a jubilee pug and a cork. He has advised that there is an inflatable device for the rear passage and would like to know if anyone has any experience as to its functionality success. Don't have problems with trying to go, but it's stopping going as I don't know that I need to go until seconds before. Haven't managed to warp time to find a loo as yet.

Annette Leach - MS Nurse: I think you are talking about the anal plug. This is a small soft synthetic suppository shape that is inserted into the rectum. On contact with fluids, this changes into a mushroom shape (still soft) in order to reduce the risk of stool leakages. If inserted properly it can be very effective. It is on prescription and you can get it through your GP. For advice on insertion, the continence advisor would be the best person to talk to.

Vinay Kalsi - Registrar in Uro-Neurology: Sounds as you need a good assessment by your continence advisor before trying any devices. If you have faecal urgency, as you describe, then biofeedback may well help. This will look at your toileting habits and teach you a toileting regimen to best cope with your symptoms.

Nigel:Thanks for the advice. I am extremely 'loose' as regards what comes out. If it had been 15 pints and a curry I would understand but I have become very much 'through the eye of a needle'. Apart from getting this plug is there any

medication apart from the stuff for holiday disasters that set you like concrete available? I'm sure we will go through this but I would like as much info as possible.

Vinay Kalsi - Registrar in Uro-Neurology: Have you seen a bowel specialist?

Nigel:No haven't seen a bowel specialist. It's just that with not knowing when I was going to go for a pee for ages and now the lack of sensation regarding the need to defecate we have assumed it was MS related. The 'loose' problem (akin to Guinness) has been around for about a year and seemed to increase with my increase in Gabapentin. Gabapentin at least stops me falling over as I was blacking out.

Vinay Kalsi - Registrar in Uro-Neurology: You would be quite right to assume the problems are MS related. Pelvic organ dysfunction (bladder, bowel,sexual) can occur as the spinal cord is increasingly affected by MS plaques, as are the peripheral nerves to the pelvic organs. Altered sensation due to nerve disruption and interruption of the normal sensory pathways up the spinal cord to the relevant higher brain centers controlling pelvic functions are quite common. The extent to which the pelvic function is affected may be reflected by the extent mobility is affected as nerves supplying the legs and pelvic organs come from the same bit of the spinal cord. Gabapentin can cause diarrhoea.

Nigel:I knew that there was a good chance that Gabapentin was the probable cause of the diarrhoea but I had unfortunately diagnosed MS before my GP and some of the consultants I was seeing at my local hospital. My legs do walk but I am charged with electric shocks, some of which can knock you off your feet. My legs also seem to resonate like tuning forks. During the day this is OK as there are distractions. It's at night time that things can go wild. Mercifully amitriptyline and I seem to get on. They normally put me in a coma so you can avoid the endless hours expecting to see blue sparks from under the bedclothes. The electric shocks have been getting more dominant into the pelvic area. I have a TENS machine which used to be helpful but I would need to wire it to the mains now to match my own body electricity. So far sexual function has not been knocked out as long as it's before taking amitriptyline.

Annette Leach - MS Nurse: There are very good website for people with bladder and bowel problems that can give lots of information about traveling and pads etc. Here are some websites for you:

Incontact

www.incontact.org

tel: 0870 770 3246

National organisation for people affected by bladder or bowel problems

Promocon

www.promocon2001.co.uk

tel:0161 834 2001

independent advice on continence products in the UK

Continence Foundation

www.continence-foundation.org.uk

Help card (Can't wait card)

small laminated card stating that you have MS and you need the toilet urgently

Available free from the MS Society

Tel: 0808 800 8000

Nigel: Thank you for that information and I shall be surfing later this evening. In the meantime it's my half hour trip to the loo as the buzzer has gone off. I go whether I need to or not. I look forward to the next chat room as it's good to get as much advice as possible. Hospital appointments seem to be on a stopwatch and by the time you have exchanged Hellos it's time to go. My last MS nurse appointment lasted a staggering 30 minutes and we got so much covered rather than the weather. Cheers and hope that everyone else contacting you this afternoon will benefit from the advice.

Rhiannon: For over six months I've been having problems - either diarrhoea or constipation and rarely anything in between. Also, have had several incontinence occurrences (joyful!). Normacol and Movicol haven't had any impact (although they have been good in the past). Dietary changes haven't had any effect. I've been referred to a colo-rectal specialist by my continence nurse. Is this an MS thing or likely to be unrelated? In all my appointments, I have neglected to ask them! Please advise!

Vinay Kalsi - Registrar in Uro-Neurology: This may well be an MS thing. I think your continence advisor has done the right thing and it will be good to get assessed properly by a colo-rectal specialist

Annette Leach - MS Nurse: I am sorry you had such a problem. Bowel problems can be related to all sorts of things, not only MS so by what you are saying the continence nurse is getting all aspects checked to ensure there is not something else going on. For example bouts of diarrhoea and constipation can be related to Irritable Bowel and this can be managed with medication and dietary advice. Ask what they are investigating for when you see your specialist

Rhiannon: I'm going in for a 'procedure' to see what's happening there but for the first time ever, I wasn't querying anything! As long as it's likely I can continue to blame MS for everything, that's fine!:) o)

Liz: I have had MS for 16 years and have had major problems with constipation. I've tried every solution, including suppositories, micro enemas and digital stimulation until I eventually developed a rectal prolapse. A year ago I had that repaired and had a hysterectomy because of large fibroids. I now have my bowels opened at least every other day as long as I have All Bran, two Fybogel sachets, 40mls lactulose, and plenty of fruit and veg. I'm interested that you say that too much fibre is not necessarily the answer as it seems to have solved my problems.

Annette Leach - MS Nurse: We do not recommend things like bran and very bulky agents if you have a slow moving bowel. Not everyone with MS will have this problem but it is something to bear in mind. To check if you have a slow moving bowel, as opposed to going into hospital for various xrays of your bowel, you can do a crude test I call the sweetcorn test. If you take a large spoon of sweetcorn with your meal, record when you took it and then monitor when you next pass it. This will give you the approximate time of your bowel passage. Normal times are females about 32 hours, males, for some reason, 27 hours. If you find it takes longer than this to pass the sweetcorn then you may well have a slowed or sluggish bowel, in which case a lot of bulky fibre will cause more problems with constipation. I hope this helps.

Sue Woodward - Nursing Lecturer: Sometimes constipation is caused by a slow transit of faeces through the gut, but sometimes things pass through OK and a person has a problem with passing the stool out of the rectum. This is called an evacuation disorder, rather than being caused by slow gut transit. Some unlucky individuals have both of these elements contributing to their constipation problem.

Liz: I forgot, I also take three dessert spoons of linseeds a day and wonder what the difference is between golden and brown seeds apart from the price? Do the golden ones have health benefits?

Sue Woodward - Nursing Lecturer: I don't know what the difference is, so I would stick with what you are using if it helps. Perhaps the place you buy them would be able to tell you

Vinay Kalsi - Registrar in Uro-Neurology: Thank you all for an excellent day of discussion. I'm afraid I must sign-off now.

Annette Leach - MS Nurse: I am also now signing off

Sue Woodward - Nursing Lecturer: And I have joined the chatroom until the close

Ali: I have suffered from long-term constipation (for four years), which is due to my MS. Three months ago I had my bowels x-rayed and the result was normal. I would like to know what the effect of long standing constipation on my bowels is. For example can it cause any kind of cancer? And what do you advise me to do?

Sue Woodward - Nursing Lecturer: I can put your mind at rest... there is no evidence that constipation causes cancer. Is the x-ray the only examination that has been done so far?

Ali: Yes, this was the only examination I have had so far. Do I need to have any other examination?

Sue Woodward - Nursing Lecturer: I don't know without having details of your constipation symptoms. It may be useful to find out if this is because of a slow gut transit, where everything is taking longer to pass through. You could try the sweetcorn test that was mentioned by Annette earlier as a very crude way of finding this out. Otherwise there are some simple things you can do....

1. Make sure you are not in a rush when going to the toilet to have your bowels open and take your time, but if they haven't moved after about 20 mins then stop and try again later in the day or the next day
2. Sit comfortably on the toilet with your feet up on a footstool and lean forwards resting your arms on the top of your legs if you are able to do this
3. Make sure you have an adequate fibre and fluid intake, but not too much

Ali: Could you please tell me how I can have the sweetcorn test and what it can show me?

Sue Woodward - Nursing Lecturer: The sweetcorn test is something very simple that you can do for yourself at home. If you take a large spoon of sweetcorn with your meal, record when you took it and then monitor when you next pass it. Sweetcorn usually passes through the gut fairly undigested and you can see the pieces in your stools. This will give you some idea as to how quickly things are passing through your gut. Normal times are females about 32 hours, males about 27 hours. If you find it takes longer than this to pass the sweetcorn then you may well have a slowed or sluggish bowel in which case a lot of bulky fibre will cause more problems with constipation.

Sian: I've suffered from MS for 10 years now, and it's only recently that I have started to get bowel incontinence. I cannot walk very far without a sudden urge to go to the toilet with explosive diarrhoea. I have contacted my GP and incontinence nurse but they have been unable to help. They put me on Movicol, which acted as a laxative rather than regulate me. They also suggested simply taking two imodium/loperamide hydrochloride. The diarrhoea seems to only occur when I am out walking. If I take the imodium I become constipated for days. Is there anything you can suggest please?

Sue Woodward - Nursing Lecturer: There is some evidence that biofeedback can help for both constipation and faecal incontinence. There are a few centres around the country offering this service and the one I link with is based at St Mark's Hospital in Harrow. We see patients from all over the county. Do you think your GP would be willing to refer you to a specialist service like this?

Sian: I live in Teesside, so I doubt she would refer me to anywhere outside the north east. Are there any websites or books on biofeedback or a closer clinic?

Sue Woodward - Nursing Lecturer: My geography is pretty hopeless, Sian. There is a centre in Rotherham General. Would that be any good for you? I don't know where all the centres are myself, but I would imagine you could find out via your GP or continence advisor which is the nearest to you. As I said these are few and far between, so you might need to travel. Good luck

Sian: Sorry I have to go now, kids need feeding. I will contact my incontinence advisor and GP again in relation to biofeedback. Thank you so much for your help. It's nice to know I'm not the only one.

Linda: The 'sweetcorn test' is interesting. I would be sure to fail every time as I only manage a bowel movement after about seven or eight days; I then go several times over two or three days (presumably clearing the backlog). Then another wait of a week or more. I presume this means that I do have a sluggish bowel? Should I cut down the fibre a bit?

Liz: The sweetcorn test sounds a good idea. If I have a slow transit time, would you suggest that I try reducing the fibre?

Sue Woodward - Nursing Lecturer: You could have a sluggish bowel and you could try cutting down the fibre a bit. Normally one could expect to have a bowel motion not more than three times per day and not less than once every three days. You could also try sitting in a relaxed position with your feet up on a

footstool when you try to open your bowels. This is a more natural position believe it or not!

Linda: Thanks for your help - I feel a post-grandchildren nap coming on!

M: Why is it that both my bowels and bladder affect my walking ability? If I need to get to a toilet urgently my legs get worse! Also if when I try and hold on when needing to pee, whilst looking And getting to a toilet it is not unusual for me to do a number two as well without any prior warning.

Jim: All my wiring down there seems pretty messed up

Sue Woodward - Nursing Lecturer: This often happens with MS. Having a full bladder or bowel can trigger an abnormal response in the nervous system. This is a noxious stimulus and can cause increased spasticity. Is this what happens to you?

Zy: I don't really have a bowel problem per se, but after let's say five or six days I find I can't go. This will last maybe just one or two days. My main concern is with my urination. When I urinate after taking all of my vitamins and minerals, my urine comes out a yellowish green. Also will get the urge to go but nothing happens. Does anyone else have urination problems?

Chris: In my experience, Bit B and other drinks (Cranberry Juice, etc) can affect colour/smell of urine a bit. Infections are easily got and affect colour/smell. Cranberry juice is really good for cleansing and regularising bladder too.

Sue Woodward - Nursing Lecturer: Sometimes this can happen with a variety of drugs as well as things that we eat naturally. Asparagus is notorious for it. I don't think this is anything to worry about. Bladder problems are extremely common in people with MS. I don't know if you have spasticity that affects your legs etc, but basically the same thing can happen in the bladder and the bladder muscle can go into spasm. This results in a sudden urge to pass urine and often results in people needing to go and empty their bladder much more frequently during the day and night. Also some bladder problems in MS are due to the bladder not getting proper messages from the nervous system to empty, so it doesn't. This can result in a feeling of needing to pass urine, but not being able to among other symptoms. Both of these problems can result in bladder leakage and both can be treated effectively, but would be managed differently depending on the cause. If you are having problems of this nature your GP should be able to arrange for a district nurse or continence advisor to assess you.

Zy: I do not feel comfortable with my doctors about the subject. I did speak with my GP and all he could say was that it was a part of MS. At that point I gave up and just said it will be with me for the duration.

Sue Woodward - Nursing Lecturer: I am sorry to hear that, Zy. Sadly this is not the first time I have come across this kind of response. Do you have access to an MS nurse? If so they may be able to go through your symptoms in more detail with you and carry out an assessment

Kate: Hi Zy. I was not happy with the way my GP seemed to think everything was MS and had to be lived with. Six months ago I changed GP and what a

difference. I have someone I can talk with, and who takes seriously managing the secondary things that occur because of MS and not being able to move properly. Patient Advice and Liaison Service (PALS) helped me do this and find the new GP. Also seeing the continence nurse helped a lot, and I could self refer to her.

Val: Hi Zy, would it be possible for you to use intermittent self cathetisation? I do and I find it great. It got rid of the embarrassing situations. Good luck

Zy: Thanks Sue for all your suggestions. I'll be signing off now. Bye everybody

Chris: With a slow bowel etc, apart from reliance on different drugs, are there other ways of managing things?

Sue Woodward - Nursing Lecturer: Yes, Chris, there are other things that you can do if you have a slow bowel and it isn't always a good idea to have to rely on laxatives if this can be avoided. Over time the laxatives such as senna etc, become less effective and you need to take larger doses with increasing frequency just to get the same effect. When patients come for biofeedback they have usually got to this stage and we advise they stop the laxatives all together. I am not suggesting you do this though! At least not without speaking to the person who prescribed them. We do use glycerin suppositories though if people can't manage.

Liz: Could you explain biofeedback to me, please?

Sue Woodward - Nursing Lecturer: Biofeedback consists of up to four appointments with a biofeedback nurse specialist at approximately monthly intervals. Each session will last between 30-60 minutes and patients will be instructed in a series of techniques that have proven effectiveness. Patients may be asked to briefly lie on their right side facing the therapist. Whilst in this position a balloon will be inserted into the rectum and inflated with 50 mls of air to stimulate a sensation of needing to have a bowel motion. The patient is then asked to expel the balloon. Patients are also taught to strain by bracing the abdominal muscles, while relaxing the pelvic floor muscles. Patients who use a finger to empty their rectum will be asked to stop doing so and laxative use is discontinued. During these appointments the therapist will also advise the patient about diet and fluid intake, frequency and length of toilet visits, timing of bowel evacuations, seating and posture for defecation. Patients also receive education about normal gut function and discussion of possible psychological or social factors that may be influencing gut function will take place. As you can see this is quite involved, but has been shown to work for about 70% of people who complete the programme

Chris: I think this is not available here (Hong Kong) yet. Any other ideas please?

Sue Woodward - Nursing Lecturer: You can try sitting in a relaxed position with your feet up on a footstool. Always try to time your bowel movements about 20-30 minutes after a meal or hot drink, eg after breakfast, as your bowel is stimulated to be most active when you have just taken something into your stomach. This is called the gastrocolic response! Make sure you have an adequate intake of fibre and fluids, but not excessive. Use the glycerin suppositories if these help. Try to train your bowel to work at the same time each day, but don't spend hours sitting and straining. Abdominal massage can help as well

Sally: Can you let me know if there is any connection between MS and IBS? If there is do that have any recommended remedies

Sue Woodward - Nursing Lecturer: I am not aware that there is any connection between MS and IBS, but IBS is known to be linked to stress and as you know, this can also make symptoms of MS worse. Regards remedies for IBS, there are some drugs that can be helpful, but in the main reducing stress can also help. I am currently doing my PhD research looking at the effectiveness of reflexology for constipation and I think that there are some other complementary thereapies that may have something to offer.

Chris: Reflexology as in foot massage? That's big in Hong Kong. Can you direct me to more information?

Sue Woodward - Nursing Lecturer: Yes reflexology as in foot massage - sort of. There have been some studies done in China and Sweden which have shown that this can help, but the research was not very large scale and so the evidence is thin on the ground. There was one research study in Israel that was fairly robust that showed that reflexology can help with bladder and bowel symptoms in MS, but this is the only MS specific one I am aware of. [Siev-Ner I, et al. Reflexology treatment relieves symptoms of multiple sclerosis: a randomized controlled study. Multiple Sclerosis 2003;9(4):356-361.]

Kate: I see a reflexologist regularly, and it is helpful. Also have contact with a remedial yoga therapist, and there are exercise in yoga that help with constipation. They are adapted so I can do them lying or sitting. Also good for keeping some flexibility in limbs.

Sue Woodward - Nursing Lecturer: I agree. I think that there are a number of complementary therapies that can help, but they don't all help everyone... it's horses for courses really. I think this is worth a try but keep an open mind about these things. Often if people believe they will be helped by a therapy, then they often are. Certainly I have had good results from reflexology I have given for constipation, although this was not in people with MS specifically. They also reported sleeping better and felleing like they had more energy. Two women even said it was better than sex!

Kate: Haven't experienced reflexology that good! I think a lot has to do with having an experienced complimentary therapist when dealing with complex chronic conditions. The one I see has a nursing background and is part of the overall management of things for me.

Muriel: I have never heard of sitting technique could you explain this please?

Sue Woodward - Nursing Lecturer: When sitting on the toilet it is more effective to lean foward with your knees raised, slight brought up towards your abdomen. Ideally if a person is too short on the toilet a step is useful in order to maintain this position. The key thing is to get the knees above the hips if this is possible for you.

If you haven't got a footstool, you can experiment with items of different heights. An upturned washing up bowl or pile of telephone directories work just as well.

The natural position to have the bowels open is actually squatting but obviously not appropriate in this day and age, so this is the next best position on the toilet.

Val: I am very troubled with flatulence. I follow a good diet but always need to use suppositories.

Sue Woodward - Nursing Lecturer: Flatulence occurs when food (usually from undigestible carbohydrate and fibre) passes from the stomach and small intestine into the large intestine without being completely digested. The bacteria in the large intestine (colon) then act on this and produce gases as a byproduct. This is perfectly natural and people can expect to pass flatus between 6-12 times a day on average. The lower part of the rectum is very sensitive and is able to distinguish between solid, liquid and gas. Sometimes people lose this sensation due to a variety of neurological and other causes and are sometimes unable to control the passage of flatus

Kath: I have a lot of trouble with flatulence. Can this be associated with M S. I think I eat a good diet but I always need to use supplements. Has anyone any advice? Thanks.

Sue Woodward - Nursing Lecturer: Flatulence is probably more related to your diet rather than the MS. When undigested foods pass into the large bowel, the bacteria there act upon them and produce a number of gases as a by product. Some foods are more likely to cause this than others - beans and high fibre foods that are not easily digested are notorious for it. Producing flatus is perfectly natural and it only becomes a problem if you are unable to control when it leaves the rectum. Constipation and needing to use suppositories, however may well be related to your MS. Have you tried anything else?

Geoff: Although OK(ish) now, I have managed to experience both bad constipation and the runs (or the 'slow hobbles' perhaps) at the same time. How is this?

Sue Woodward - Nursing Lecturer: Sometimes when people become badly constipated, faecal fluid can bypass the solid matter in the rectum and it appears like diarrhoea, which can be difficult to control. This sounds as though it could have been the case for you.

Geoff: Could well be - when the worst of the constipation was sorted, the other problem seemed to go too.

Jenny: Having read all the questions and the answers, I am very sad for all these people suffering both faecal and urinary incontinence. I firstly had a urostomy because all other methods had failed to even assist with my bladder incontinence. I was not surprised that when they removed my bladder it was the size of a walnut. The faecal incontinence started shortly afterwards - bouts of very loose faeces followed by bouts of constipation. Having learned my lesson with the urinary problems, I requested a colostomy. Now I have two bags and all is well. Before both ops I was told I may die, but that was better than living with incontinence and I and my family readily accepted the situation.

Sue Woodward - Nursing Lecturer: I am sorry to hear that you have had both bladder and bowel problems, but at least you have found a solution that works for you. Colostomy is not usually performed unless as a last resort, but I can understand your feelings about this. I assume you had an indwelling catheter for some time before your urostomy, would this be correct? This would certainly cause the bladder to shrink down around the catheter tip to something the size of the walnut you mention.

Jenny: Yes I did have a supra-pubic catheter but it did not work - kept bypassing

TAB230: I too have suffered continual UTI's and the prolonged antibiotics resulted in faecal incontinence. Transferring from my wheelchair to the toilet became a problem following my baclofen pump fitting. I had a colostomy and feel my independence has returned as I change my bag when necessary. Nothing is more degrading than having to lie there whilst you are cleaned. I am still learning which foods are tolerable. I feel everyone should have a colostomy. It's fabulous.

Sue Woodward - Nursing Lecturer: Colostomies can be an answer for a lot of people, but they aren't for everyone. Some people find that they would not be able to cope psychologically with dealing with one, in the same way that some people never get on with intermittent self catheterisation because they can't bear the idea of it

TAB230: Live for the moment. Colostomy? Catheter? Means to an end

Geoff: Mirrors my thoughts about my wheelchair - a solution not a problem (mind you, took years to come to that view).

Tabooang: I was diagnosed with a lazy bowel two years ago and take Movicol & suppositories to manage this. I hate having to rely on suppositories every other day. Is there any other way I could manage my bowels?

Sue Woodward - Nursing Lecturer: Excuse me if I copy one of my previous answers here for you as it took quite a long time to type out! You can try sitting in a relaxed position with your feet up on a footstool. Always try to time your bowel movements about 20-30 minutes after a meal or hot drink, eg after breakfast, as your bowel is stimulated to be most active when you have just taken something into your stomach. This is called the gastrocolic response! Make sure you have an adequate intake of fibre and fluids, but not excessive. Use the glycerin suppositories if these help. Try to train your bowel to work at the same time each day, but don't spend hours sitting and straining. Abdominal massage can help as well

Biofeedback can also help, but there are not many centres in the UK offering this treatment. Biofeedback consists of up to four appointments with a biofeedback nurse specialist at approximately monthly intervals. Each session will last between 30-60 minutes and patients will be instructed in a series of techniques that have proven effectiveness. Patients may be asked to briefly lie on their right side facing the therapist. Whilst in this position a balloon will be inserted into the rectum and inflated with 50 mls of air to stimulate a sensation of needing to have a bowel motion. The patient is then asked to expel the balloon. Patients are also taught to strain by bracing the abdominal muscles, while relaxing the pelvic floor muscles. Patients who use a finger to empty their rectum will be asked to stop doing so and laxative use is discontinued. During these appointments the

therapist will also advise the patient about diet and fluid intake, frequency and length of toilet visits, timing of bowel evacuations, seating and posture for defecation. Patients also receive education about normal gut function and discussion of possible psychological or social factors that may be influencing gut function will take place. As you can see this is quite involved, but has been shown to work for about 70% of people who complete the programme.

Taboang: Thank you for that information, I will look into a biofeedback centre near me.

Sue Woodward - Nursing Lecturer: If anyone reading this thinks they would like to be referred for biofeedback, for either constipation or faecal incontinence, referrals can be made to Professor Christine Norton, Nurse Consultant in Bowel Continence in the Physiology Department of St Mark's Hospital, Harrow. Referrals can be made by GPs or by other hospital consultants. We also run a neuro bowel clinic once a month. If people are unable to get to Harrow, there are other centres around the country, which may be able to help.

Stephen: I have a problem passing urine - and do say if it isn't the right place to ask advice on this. I often want to pass urine (have done since I was a child - always being the one who 'wanted to go'). I was diagnosed with MS three years ago. Over the last year or so, peeing has become more difficult. My bladder often feels like it is ready for me to pee, but I cannot seem to work out whether to strain or to relax. Sometimes it is easier if I lean forward with my arms on my knees. Often though I only pass a small amount of urine and I still feel the need to pee. This gets incredibly irritating - in meetings, on planes, at night when going to bed, or if I wake in the night. One solution I use is to drink and drink and then wait until I know my bladder is really full. This seems to work reasonably well if I can live through the irritating need to pee. But I'm finding this constant feeling of needing to pee, but being only able to pass a tiny amount, a real nuisance. Has anyone any advice?

Sue Woodward - Nursing Lecturer: This is a very common problem in people with MS and is caused by a lack of co-ordination between the bladder muscle trying to empty and the sphincter (ring of muscle at the bladder neck that keeps it closed) not relaxing to allow the urine to exit the bladder. When this happens, the bladder is unable to empty properly so you are left with the sensation of needing to go, even after you have passed some urine. If you lean forward, the pressure inside your abdomen rises and pushes down onto the full bladder forcing some urine out through the bladder closure mechanism. As the bladder is not emptying fully, it doesn't take long to fill up again, so you feel the urge to go frequently. Other symptoms include difficulty getting going, a poor flow, sometimes a bit of dribbling after you have finished. The danger with this is that the urine left in the bladder can lead to infections and the bladder needs to be drained. The usual solution to this would be to carry out intermittent self-catheterisation. I would suggest that you speak to your GP / MS nurse / district nurse about this symptom sooner rather than later so that a proper assessment can be done and the volume of urine left in your bladder can be measured to see if this is in fact the problem.

Caroline: I have had primary progressive MS for four years and use a wheelchair. I have some bowel urgency which I deal with by eating a suitable diet and trying to stick to a routine of 'going' everyday. My query is this - every so

often I get so that I don't go for days - eg a week - at a time and I feel horribly bloated etc, yet when I do go I find I haven't been constipated in the sense that the stool is just as soft etc as normal. What is going on? Is this to do with my MS? It bothers me because I don't have all that much control over when I go, so once the routine is lost I am at risk of getting caught short.

Sue Woodward - Nursing Lecturer: This could well be due to your MS and it is still possible to be constipated with a soft stool. You sound like you are doing the right thing by keeping control of your diet and you know which foods affect you. Bloating is a common side effect of constipation, so it makes sense that you suffer from this as well.

Roz: Sometimes I have accidents even though I don't realise I need to go to the loo. Seems like a gippy tummy, but I don't feel ill when it happens

Sue Woodward - Nursing Lecturer: It may be that you are losing some of the sensation in your rectum, which can happen with MS. This means that you are not always aware when you need to go and can leak a bit. If this becomes a significant or persistent problem then we would normally recommend bunging you up with something like loperamide and then using suppositories to make your bowel emptying more controlled and predictable

Kate: Thanks to everyone. The chatroom has done much to reduce my fears about what happens if things get worse. I just need to persist in getting appropriate help. Think all the taboos about incontinence make matters harder.

Geoff: It is a difficult area to talk about. People can just about accept bladder problems, but bowels are a real no no. And that makes living with it all the harder

Sue Woodward - Nursing Lecturer: I couldn't agree with you more about the whole problem with talking about things like this. Hopefully it will improve. A few years ago we would never have had adverts on the television for incontinence products, however much I disagree with the message they are giving! If you look around the birthday cards there are plenty out there about poo these days, so perhaps things will become more acceptable in the long-term. I can't see the problem myself - I spend all day talking about bowels!

Trulyscatty: Why does my bowel and bladder make my mobility worse?

Sue Woodward - Nursing Lecturer: Bladder and bowel problems can make your mobility worse because they act as a noxious stimulus to your nervous system. Because of the MS, the body's response to this is abnormal and you end up with an increase in spasticity

Roz: Can you explain noxious stimulus please

Sue Woodward - Nursing Lecturer: A noxious stimulus is just something unpleasant, such as the sensation of a full bladder or bowel. It is the nervous system that transmits these messages to the brain normally, but in MS the message triggers the abnormal response as well

Trulyscatty: Why is it when I want to get to the toilet for a pee, if I have held on for as long as I can I often find when getting to a toilet I need to poo as well but had no indication before reaching the toilet?

Sue Woodward - Nursing Lecturer: You may find that you open your bowels at the same time as emptying your bladder because both of these structures empty through the same pelvic floor muscles. As you relax the pelvic floor to empty your bladder, the bowel can empty as well. The rectum is constantly filling up with stool, which arrives there in stages. There is a mechanism at the lower end, near the anus, that samples the contents regularly and only when there is sufficient stool there to stimulate the nerve endings that are activated when the rectum is stretched, do you feel the urge to have your bowels open. This does not mean that you don't have stool in your rectum if you can't feel it.

Trulyscatty: Sometimes I have the urge to empty bowels but nothing seems to happen. It's like I can't squeeze it out. The stool is not hard but soft. Other times I am very constipated. Other times no urge to empty but strong urge to empty bladder but have to hold on etc. I get slower mobility-wise then by the time I reach the loo, I need to poo same time as pee if that makes sense?

Sue Woodward - Nursing Lecturer: It does make sense and it is the unpredictable nature of these things that makes it so difficult to manage for some people. You can still be constipated with a soft stool, just in the same way as you can with hard pelleted stool. Sometimes the pelvic floor muscles aren't coordinated properly to relax when they need to for you to pass the stool out and this can happen in MS

Trulyscatty: Many thanks for your replies! One more question why does Movicol and/or Fybogel takes at least three days before it takes effect?

Sue Woodward - Nursing Lecturer: Fybogel works by being difficult to digest and therefore staying in the gut, bulking out the faeces and attracting water into the gut. Normally water would be absorbed from the colon, large bowel, but Fybogel makes sure the water is retained which makes the stools easier to pass. In order for it to work, it has to pass through the gut and this can take a day or so. Also for it to work, a person's fluid intake has to be adequate.

Caroline: Sorry, can I just ask something further from my earlier question? When I described being constipated but with loose stool, is this the same as a sluggish bowel, as discussed earlier in the session? And I find I don't have much voluntary control - I might be able to delay going for 5-10 minutes once I have the urge, but I cannot possibly go when I do not have the urge. Is this the same problem, or is there also a problem with the muscles/ sensation in my rectum?

Sue Woodward - Nursing Lecturer: Is this liquid we are talking about or a soft formed stool? Certainly sensation in the rectum and the normal reflexes that control bowel actions are affected by MS so you may well find your body's response to the urge is altered.

Caroline: It's a soft formed stool

Sue Woodward - Nursing Lecturer: I have looked back at your previous description and what I think you are describing is more likely to be an evacuation problem due to lack of co-ordination of the muscles around the pelvic floor that control bowel emptying, rather than the sluggish bowel.

Caroline: Thanks you've been really helpful. I haven't been sure whether I'm imagining my difficulties but it doesn't feel as if I am and it's good to be able to ask someone about them.

Simon - MS Trust: It's just about 7 now, so we'll wrap it up. Thanks to Sue and to Annette and Vinay earlier in the day. Also many thanks to all the people who asked questions and shared comments.