

WRSG Newsletter

WOLVERHAMPTON RHEUMATOLOGY SUPPORT GROUP

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CARING IS SHARING

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The WRSG yearly subscriptions are due in June. Committee have agreed to keep the charge at £5 per person and £8 per couple. If you became a member of the WRSG in 2008 your subscriptions are not due until June 2009.

Remittance advice slips are enclosed with this newsletter for members whose payment is now due and a prompt response would be appreciated.

Please make cheques payable to the WRSG and send them direct to our Treasurer:

Reminder

Information Session

We have arranged an Information Session about the benefits system on the morning of the 17th June, at the Holly Bush from 10.30 to 12.30 a.m. We will provide tea, coffee and cakes on arrival.

The talk will be given by Denise Pearson a Welfare Rights Officer working for Wolverhampton City Council. They are based at Heantun House, Salop Street Wolverhampton and undertake benefit advice and benefit take up campaigns for the Social Services department.

Admission slips for those who have requested a place are enclosed with this newsletter.

We have not had a very good response for this event and I now realise that because the May newsletter was so late reaching you I didn't give much time for you to respond. If you have not sent in a booking form but would like to attend this event just give me a call and I will add you to the list.

I know from personal experience that everyone is not claiming monies they are entitled to so come along and make sure you are!

Dorothy



I am sorry the May newsletter did not reach you at the usual time and I said I would explain in this edition.

I spent three weeks in New Cross Hospital.

This was all a continuation from my article entitled "Who should I trust" in the May newsletter.

I had a circulation problem in my left foot and lower leg. I had ulcers breaking out and I was being attended by the District Nurses.

I couldn't seem to make anyone understand how much pain I was in. I asked for a visit from my GPs but they wouldn't come out I was just sent some stronger pain killers which if they had bothered to check, my records would have shown I couldn't take I was also put on a different blood pressure tablet to replace the ones which were not suitable for me after many years.

On Tuesday 15th April the District Nurse was very worried about my leg and she rang my Doctor. He wouldn't speak with her. She rang back and asked the Practise Nurse to fax a letter to the Emergency **Assessment Unit at New Cross and she rang** for an ambulance. I owe that District Nurse a considerable debt for her help. Kath came round and packed a bag for me and the ambulance arrived at 12.00 noon. I do not know how I would have managed the seventeen days I was in hospital without Kath and Tony. Kath took my keys and took over looking after my house, my post, my washing and they visited me often along with Esme, another friend.

I was quite impressed with the EAU. I was swabbed for MRSA. I had a blood pressure check and an ECG. I was seen by a doctor who fetched his boss who was a Vascular Consultant He said I should be admitted. After a four hour wait I was given a bed on the Emergency Short Stay ward. I was told that ward was for a four day stay. Little did I know I would be there for sixteen days

On Wednesday morning a team of Doctors came to see me. They went and one of them brought his Consultant to see me.

Later that morning a Surgeon came and he said "I don't think you have blood clots in your main arteries, I think your Rheumatoid Arthritis has damaged the little veins in your foot" Then he said "Unfortunately there is not a lot I can do other than amputate." Well I couldn't tell you how I felt. Shocked, upset and I didn't hear much of the conversation after that. He later said that I was not ready for that and that I could keep my legs!

He handed me over to a Medical Consultant colleague who set about solving my problem. On the Friday I had an MRI scan. For anyone who has had one these MRI scanners have a language of there own don't they?

The MRI scan revealed that I had blood clots in both groins. The Consultant who had taken over my care said I needed an Angiogram but that I couldn't have that until a week on Monday. I was put on Aspirin and Antibiotics plus other drugs. This consultant explained everything to me and I was grateful for that.

Then my troubles began. On the Saturday four of us in our bay went down with the Novovirus which was awful. I was sick all the weekend. On the Tuesday I was moved to another bay and caught it again so I was sick all day Wednesday. On Friday I came back to my bed from the toilet. I put my walking stick on the chair and I held on the table which went from under me and I ended up on the floor. I had a cracked rib, two black eyes and two badly bruised arms and I hurt all over. From then on it was difficult to look after myself. I couldn't sit up in bed, wash myself or go to the toilet on my own.

I then realised that this ward was suitable for walking wounded who could take care of themselves but it was a real obstacle course for the likes of me. The staffing skill mix particularly on the early shift is, in my opinion not correct. When I am mobile and I feel better I intend to ask for a meeting with the appropriate person to discuss this.

There is one nurse to eight patients on the bay and I couldn't work out if there were one or two Auxiliaries. The nurse has to do the drugs round, check all the drips etc. give injections, do dressings and accompany the doctors or consultants when they do their round. The auxiliaries have to do the drinks round, breakfasts, make the beds and help with the observations. If you can get washed and dressed etc you are o.k. but if like me and several other patients vou needed help it is not very forthcoming. They would put a bowl in front of me but as I couldn't even stand to get my nightie off I didn't get very far washing by myself. It isn't anyone's fault that the tender loving kindness is no longer there it is all down to time and money.

I had difficulty getting on to my bed and I kept sliding down the bed and hadn't the strength in my arms to pull myself up. My bottom and heels were getting sorer by the day and I couldn't even pull the blankets over me. I would just lie there and then say to someone could you cover me up please? It would never enter their heads to look and see if a patient was comfortable because they do not have the time. I couldn't eat by this time after the sickness and they did order me some Fortisip drinks to build me up and I think they helped.

I had the Angiogram on the Monday and the Nurse had to come and fetch me back with the Porters. That meant she was away from her other seven patients and she had to catch up when she came back. The Nurses very rarely leave on time at the end of their shift.

I waited a further four days for the results of the angiogram and what was to be my treatment. Did I require surgery or medication? On the Thursday evening I was told I was being moved to D.14 Care of the Elderly. I didn't mind that because I thought at least they would have time to care for me and realise how fragile I was No such luck. I was put to bed with a glass of water. In the morning I asked if my slippers could be put on to go to the toilet and I had to wait quite a while.

By nine thirty we hadn't had a cup of tea so I asked if we had a drink and breakfast on that ward. I was told in a minute.

I asked an auxiliary on that ward if she would open a bottle top for me and she replied "How would you open it at home?" I said with nutcrackers and she said bring them in them. I said if I brought in everything I used at home they wouldn't get near my bed and was it too much to ask. They promote independence but as you all know I am usually independent. They do not know their patients or bother to get to know them.

By this time I had decided I had had enough and was going home where at least everything is within my reach and manageable. I phoned a friend who works at New Cross hospital on my mobile and asked for help. She came to see me. She contacted the Consultant who said there had been an improvement in the blood clots between the MRI scan and the Angiogram and that I could come home on medication to thin my blood.

After seventeen days I was very disillusioned. I came home after two bouts of sickness and with a cracked rib, two black eyes and bruised arms. What I think was worse was that I also came home hungry and dirty.

I was brought home by two caring ambulance staff who took me right into my lounge in the wheelchair. Greg came and put me to bed. He said he needed to see that I was safe before he drove away. On Saturday morning although I felt very ill and weak I washed my hair, had a bath and set about my recovery.

My neighbours Kath and Caroline are doing a wonderful job in looking after me without any fuss. They do me some meals and pop in daily to see what need. How marvellous they are and I really do appreciate it. I will find a way to thank them when I am better. I would also like to thank our members Joan Young and Margaret Wall for visiting me.

Thank you to all the friends who sent "Get well Cards" and who have visited me since I returned home and of course Liz who visited and has taken me for hospital appointments.

When I was on the Emergency Short Stay ward a young girl came in suffering with Asthma. She decided to befriend me. She asked if she could use my mobile to send a text. I agreed. She didn't have any orange juice so I gave her mine. Then she wanted to go to the shop and I gave her £2. Later she wanted to top up her mobile but I thought enough was enough. One lunch time she was missing and the staff asked where she was. We didn't know. She was still missing at tea time so they changed her bed and admitted another patient. At 10.00 p.m. she turned up expecting her bed to still be there. I asked her where she had been and she said her Brother had taken her to visit her family in Bewdley. She said she was admitted to New Cross at least once a week. I think she felt safe in there and frightened when she was alone.

Alison and Ashley's Wedding

I had two weeks after I came out of hospital to get well for the wedding which we had been looking forward to for a very long time. I had my outfit apart from a hat and Kath got me a Fascinator for my hair.

Greg, Ann and the children picked me and the wheelchair up on Friday after school and we were off to Wales. I was looking forward to the event but I was quite worried about how I would cope. Greg was Ashley's Best Man, Jessica was a bridesmaid and Jack an attendant in the same dress suit as the men! I didn't want them to have to spend too much time looking after me.

The wedding and reception was at the Wild Pheasant Hotel Llangollen After sorting out our rooms in the hotel we had an evening meal and then I went to bed. Jack immediately took charge of pushing me in the wheelchair and I couldn't have wished for a better friend for the whole weekend.

Jack worked hard welcoming the guests and he carried the rings on a little black cushion up to Ashley and Alison. He took his job very seriously. Ann did the dressings on my leg for me and she made an excellent nurse. Ann also looked lovely on the day.

On Saturday the day of the weeding they came for me and we went down to breakfast at 8.00 a.m. Jessica and Alison were going to have their hair done at 9.00 a.m.

Jack took me back to my room and stayed with me watching TV until it was time to get changed for the ceremony.

Alison looked beautiful in her dress with a long train. Jessica was one of three bridesmaids and they looked very pretty in pink. The men including Jack all wore matching suits. Greg went to fetch Ashley from home and we went down at 12.00 to meet all the other guests before the wedding at 1.00 p.m.

The service was very moving. I usually shed a tear as the bride walks up to the groom and this was no exception. Tears of happiness though aren't they but very emotional. A lady played a harp throughout the service and reception which created a lovely atmosphere.

The meal was delicious and the speeches were quite funny. I was very proud to sit between my two sons and listen to their speeches about each other.

I went for a rest between the actual wedding and reception and the evening reception and I stayed down until 11.00 p.m. It was great to see many of the members of my family and also to catch up with Alison's family who I only see at Christmas.

We came home at lunch time on Sunday and I was exhausted but very happy to have made it. The photographs should be good. Jack wheeled me every time the photographer needed me and then took me and the wheelchair out of the way until I was needed again and of course I managed to stand for the photographs. I am looking forward to getting a set of them.



Ashley and Alison Darby 17th May 2008



Dorothy, Ashley and Alison



Back – Left to right Jack, Greg, Jessica and Laurie – Front left to right Ashley, Danielle and Alison



A very unusual cake



Dorothy and my pal Jack

The cake was based on the hotel. The bottom was the reception area with the staircase leading up to the penthouse suite which Alison and Ashley stayed in and on the top of the cake were models of Alison and Ashley relaxing there.

So far this newsletter has been all about my stay in hospital and the wedding but as I haven't done anything else I found it difficult to find anything much to write about. That is my excuse and I am sticking to it !!!!

I hope it wasn't too boring!!!'

The following very moving piece was sent to us from Julie Stead

This has been kept alive and moving since 9/11. In memory of all those who perished this morning; the passengers and the pilots on the United Air and AA flights, the workers in the World Trade Centre and the Pentagon, and all the innocent bystanders. Our prayers go out to the friends and families of the deceased.

IF I KNEW

If I knew it would be the last time That I'd see you fall asleep, I would tuck you in more tightly and pray the Lord, your soul to keep.

If I knew it would be the last time that I see you walk out the door, I would give you a hug and kiss and call you back for one more

If I knew it would be the last time I'd hear your voice lifted up in praise, I would video tape each action and word, so I could play them back day after day.

If I knew it would be the last time, I could spare an extra minute to stop and say 'I love you,' instead of assuming you would KNOW I do.

If I knew it would be the last time I would be there to share your day, Well I'm sure you'll have so many more, so I can let just this one slip away.

For surely there's always tomorrow to make up for an oversight, and we always get a second chance to make everything just right.

There will always be another day to say 'I love you,' And certainly there's another chance to say 'Anything I can do?'

But just in case I might be wrong, and today is all I get, I'd like to say how much I love you and I hope we never forget.

Tomorrow is not promised to anyone, young or old alike,
And today may be the last chance you get to hold your loved one tight.
So if you're waiting for tomorrow, why not do it today?
For if tomorrow never comes, you'll surely regret the day,

That you didn't take that extra time for a smile, a hug, or a kiss and you were too busy to grant someone, what turned out to be their one last wish.

So hold your loved ones close today, and whisper in their ear, Tell them how much you love them and that you'll always hold them dear

Take time to say 'I'm sorry,'
'Please forgive me,' 'Thank you,' or 'It's okay.'
And if tomorrow never comes,
you'll have no regrets about today

Joey and Ben

Joey wanted to be a soldier, So he told his best friend Ben Joey was only nine years old. And Ben was almost ten.

Both grew to be tall fine lads, Still friends as in childhood days, Then Joey joined the army, But Ben drifted into bad ways.

Joey was posted overseas Such a brave courageous lad, Whilst Ben did drugs every day, Stealing and spending every penny he had.

Then Joey came home highly decorated A brave example to his men But he cried when he heard what had happened The death of his old friend Ben

Joey remembered their childhood days Those happy lazy days in the sun, The mock battles they had fought together, But only one had been won.

Bren

That one reminded me of "Two Little Boys"

I received the following from Sandra Knights

TWO GLASSES OF WINE

When things in your life seem almost too much to handle, when 24 hours in a day are not enough, remember the mayonnaise jar and the 2 glasses of wine theory...

A professor stood before his philosophy class with some items on his desk in front of him. When the class began, wordlessly, he picked up a very large and empty mayonnaise jar and proceeded to fill it with golf balls.

He then asked the students if the jar was full. They agreed that it was.

The professor then picked up a box of pebbles and poured them into the jar. He shook the jar lightly. The pebbles rolled into the open areas between the golf balls. He then asked the students again if the jar was full. They agreed it was.

The professor next picked up a box of sand and poured it into the jar. Of course, the sand filled up everything else. He asked once more if the jar was full. The students responded with a unanimous 'YES.'

The professor then produced two glasses of wine from under the table and poured the entire contents into the jar, effectively filling the empty space between the sand. The students laughed.

'Now,' said the professor, as the laughter subsided, 'I want you to recognize that this jar represents your life. The golf balls are the important things; your family, your children, your health, your friends, and your favourite passions; things that if everything else was lost and only they remained, your life would still be full.

The pebbles are the other things that matter like your job, your house, and your car. The sand is everything else; the small stuff. If you put the sand into the jar first', he continued, 'there is no room for the pebbles or the golf balls. The same goes for life. If you spend all your time and energy on the small stuff, you will never have room for the good things that are important to you.

Pay attention to the things that are critical to your happiness. Play with your children. Take time to get medical checkups. Take your partner out to dinner. Play another 18 holes. Do one more run down the ski slope. There will always be time to clean the house and fix the disposal. Take care of the golf balls first; the things that really matter. Set your priorities. The rest is just sand.'

One of the students raised her hand and inquired what the wine represented.

The professor smiled. 'I'm glad you asked. It just goes to show you that no matter how full your life may seem, there's always room for a couple of glasses of wine with a friend.'

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As Chair of the WRSG and the Black Country Lymphoedema Support Network I receive information on products which may be of help and interest to our members I haven't tried this product but it does sound interesting.

The Physio-Master vascular cushion was invented by a Physiotherapist at the Princess Royal Hospital in Telford. The cushion is self inflating and consists of 4 chambers of air that offer resistance when feet are placed on it in a standing or sitting position.

Standing on the cushion helps with balance control and postural stability.
Using the cushion when seated aids venous return, improving the circulation.
It can also be used to sit on or folded in half as a back support when seated.

The Physio-Master normally retails at £24.99, but is offered at a reduced cost of £23.00 to members of this group. To obtain this discount please quote Ref RL4014 when placing your order.

For further details contact Medical Devices Technology Ltd on 01902 778380, email sales@mdti.co.uk and www.mdti.co.uk

Royalties from sales are directed back into the NHS where the product was invented.

Our visit to the Houses of Parliament

First of all my thanks go to Rob Marris MP for obtaining passes for our tour.

When we entered the Houses of Parliament our guide explained the history of all we saw. The tour lasted nearly two hours. We were allowed to sit down at various points and time went by very quickly.

The party seemed overawed by the wonderful heritage we have. A good time was had by all and even the sun came out to greet us on our way home

Visit to Historic York

<u>Friday</u> – What can we say? The weather was perfect and we had a good journey. At the hotel a wonderful selection of food was presented.

<u>Saturday</u> - We visited York, York Minster, The Shambles and various Squares which had entertainment on which really made our day.

Sunday – On our way home we stopped at a large shopping complex, Lakeside. There was lots of seating and café's. Nearly everyone bent the plastic as the saying goes. We had a very enjoyable weekend.

Joyce Knibbs

I receive many letters and telephone calls from Margaret Wall.

Margaret has written asking me to pass on the following information.

NEED A LIFT

Call a Volunteer Scooter Driver!

If you are an out-patient or a visitor and are finding it difficult to walk to he department you need, call our Volunteer Scooter Driver to take you there- free of charge.

Just call 07964 291 419 or ask a member of staff to do so for you.

This is from Pauline and Tony Callaghan I always like to finish the newsletter with something to make you smile!

A Scouser joke doing the rounds...

An Australian, an Irishman and a Scouser are in a bar. They're staring at another man sitting on his own at a table in the corner He's so familiar, and not recognising him is driving them mad.

They stare and stare, until suddenly the Irishman twigs: 'My God, it's Jesus!'

Sure enough, it is Jesus, nursing a pint.

Thrilled, they send him over a pint of Guinness, a pint of Fosters and a pint of bitter.

Jesus accepts the drinks, smiles over at the three men, and drinks the pints slowly, one after another.

After he's finished the drinks, Jesus approaches the trio.

He reaches for the hand of the Irishman and shakes it, thanking him for the Guinness.

When he lets go, the Irishman gives a cry of amazement: 'My God! The arthritis I've had for 30 years is gone
It's a miracle!'

Jesus then shakes the Aussie's hand, thanking him for the lager.
As he lets go, the man's eyes widen in shock. 'Strewth mate, the bad back I've had all my life is completely gone!
It's a Miracle.'

Jesus then approaches the Scouser who says, 'Back off, mate, I'm on disability benefit.

Disclaimer:

The views expressed in this newsletter are taken in good faith and are not necessarily endorsed by the editor or the WRSG. The use of a product name does not constitute an endorsement or a recommendation by the WRSG