

WRSG Newsletter

WOLVERHAMPTON RHEUMATOLOGY SUPPORT GROUP

CARING IS SHARING

Issue Number 77

Charity No. 1041181

JULY 2008

Editor:

Dorothy Darby

Telephone: 01902 654417 E-mail <u>Dorothy.darby@blueyonder.co.uk</u> Web: <u>www.wrsg.org.uk</u>

<u>Contents</u>: Announcements Features Poems

Subscriptions Reminder

£5

The WRSG yearly subscriptions were due in June. Committee 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 were enclosed with the June newsletter for members whose payment is due. Thank you to the members who have paid. Receipts are enclosed with this newsletter.

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

<u>NHS 60 Service of Celebration</u> <u>Wednesday 2nd July 2008</u>

I am delighted to have been invited to Westminster Abbey for the above celebration. When I received my invitation at the end of May I thought I couldn't manage it but after the wedding I thought yes I can go with help.

Pat Jones is coming as my carer and I know I will be in good hands.

I am going as a wheelchair user so that we can have seating suitable for disabled access.

I am now looking forward to the event and will have a chance to wear my wedding outfit again.

<u>Mayoral Reception for the NHS 60th Anniversary/Birthday – Monday 7 July 2008</u>

I have also been invited to the above celebration and again I am thinking why not. Just because I cannot walk far or drive does not mean my life has to be put on hold. I do wish some of my pain would go away though.

June Osborne is coming with me to help! Dorothy

<u>A date for your diary</u>

WRSG AGM

We have booked the WRSG Annual General Meeting for the evening of Monday 1st September at the Hollybush Penn Road Wolverhampton More information at a later date

<u>I have been asked to print the following</u> <u>article which is self explanatory</u>

This article has been generated as a result of my visit to Dorothy to take her a wheel chair on her discharge from New Cross Hospital and following reading her account of her stay in New Cross (June 2008 Newsletter)

Following my visit to Dorothy after her hospitalisation I drove home with feelings of shame in that I was a Nurse and even more feelings of shame that I used to work at New Cross Hospital. What a sad indictment on so called caring professions to have a patient leave hospital, "hungry and dirty." The more I thought about what Dorothy had told me about her experiences in Hospital the angrier I became.

Dorothy is an honest, intelligent, brave woman whom I first knew as a patient at New Cross and later whilst in a managerial role I had many meetings with her; I have no reason to doubt her description of her treatment now.

I lay blame for the development of the situations Dorothy describes at the door of the Director of Nursing, does she not realise that Rheumatoid Arthritis sufferers have special needs and require nursing by nurses who are specially trained in the care of R.A. patients and above all have an interest in the condition, but sadly it is not a disease that has targets attached to it and the trend is also to encourage nurses not to specialise in a particular field of nursing.

How is it that I needed 2 years of additional training in Orthopaedics and Rheumatology before I had an inkling of what some one with that condition is going through? Many of these sufferers look healthy belying the fact that inappropriate handling can damage and dislocate joints (not to be confused with Osteoarthritis). The Auxiliary Nurse Dorothy speaks about I am sure thought she was doing her job maintaining so called independence, she is not trained in the intricacies of that disease. Dorothy is also clear that there was insufficient staff, and more likely the wrong skill mix on the Emergency Short Stay Ward and the care was not forthcoming on the Care of the Elderly Ward to adequately care for elderly dependent patients.

I wonder when the Chief Executive and his team leave New Cross Hospital having reversed the financial slide if they will also think perhaps is it in tandem with the quality of care slide.

I would also like to add that Dorothy's experiences are not isolated. Our group has many other disillusioned members following their stay at New Cross hospital.

Pat Jones Patient Advocate Equipment officer Wolverhampton Rheumatology Support Group

My hospital experience

I would like to take this opportunity to thank all the people who have sent me get well cards, and very interesting letters since my article in the June newsletter. Thank you also for all your telephone calls and visits.

Since my return from hospital I have received excellent care from the Wolverhampton District Nurses.

I have only encountered one problem, If you attend the hospital you can ask for Patient transport to hospital and your circumstances will be taken into account.

There is absolutely no facility for this in the community.

If you have to attend a medical Centre for blood tests etc., you just have to make your own way there. I find this a little disappointing when you consider that the Trusts are working towards Care are Closer to Home and Care in the Communities.

I think I may look into this!

Dorothy

When I expressed my concern that the nurses didn't have time to give the patients tender loving care during my stay in hospital I didn't anticipate them being replaced by robots!

Robot nurses will be used to clean hospital wards by 2020

Nurses could be delegating tasks to robotic colleagues by 2020, according to researchers who unveiled two prototypes at a Midland university yesterday.

The devices, part of a three-year 2.7 million Euros (£2.16 million) project, can collect prescriptions and clean spillages, enabling nurses to spend more time with patients.

Researchers at Warwick University embarked on the IWARD - Intelligent Robot Swarm for Attendance, Recognition, Cleaning and Delivery - project, supported by European Union funding, in January 2007.

Although the robots - which cost 15,000 Euros each - look more like computers, they have already proved their worth in a trial at a hospital in San Sebastian, Spain, last year.

A third 'robo-nurse' will be completed by experts based at the Warwick Manufacturing Group, by late summer, and a team of robots will be put through their paces on the wards of a British hospital either in Cardiff, Newcastle or Warwick, where three of the ten research teams are based, by the end of 2009.

Professor Vinesh Raja, leading the research at Warwick University, explained how the computerised assistants would be able to identify human staff, "by scanning their eyes or fingerprints."

He added: "Nursing staff will be able to alert one of these robots via a handheld device, like a BlackBerry, and tap in instructions to collect a certain drug or to go to a particular ward to clean up a spillage. "We hope to develop it further so they can respond to spoken commands and physical gestures, but results of the first hospital trial in Spain have been very good "I do think that by 2020 we will see teams of robots working alongside human staff in British hospitals, but they could also serve a vital surveillance role in many other public places, such as shopping malls and airports, in light of terror threats."I believe this will happen because health-care sectors around the world are not able to cope with patient demands and we have to come up with more inventive ways of improving efficiencies in our hospitals.

"This will relieve nurses of some of their more menial duties, giving them more time to spend with patients."

---00000----

Tormented by arthritis? In this amazing £20,000 suit, a leading TV scientist says

I FEEL YOUR PAIN

It is a simple movement - and one I usually carry out without a second thought. Taking a few coins from my pocket, I accidentally drop one. Instinctively, I go to squat to pick it up, but find myself in more of a semicrouch, unable to fully bend my knees and hips. Reaching to retrieve the coin, I claw at thin air. No matter how hard I try, I can't fully extend my arm as my elbow won't straighten. My finger joints are stiff and I can't make a fist. Even if I could reach the coin, I would not be able to grip it. Pain shoots up my leg as a bunion cuts into my foot and I lose my balance. With my arm and leg joints so immovable, there is nothing I can do to stop myself from falling over. Sprawled across the kitchen floor like an upturned woodlouse, I realise I'm stuck the stiffness in my limbs makes it impossible to right myself.

It's humiliating, and I'm only thankful this has happened in the privacy of my own home rather than on a busy street. But my feelings are minor compared with the genuine fear that this scenario must bring to millions of arthritis sufferers in the UK. My precarious situation is due to an 'arthritis simulation suit' - the only one of its kind. Costing £20,000, it was developed by the Ergonomics and Safety Research Institute at Loughborough University. It mimics the characteristics of arthritis to give an insight into the pain and impaired quality of life experienced by sufferers.

Essentially it is a boiler suit with sewn-in splints and restrictors to limit movement of joints such as the hands, wrists, elbows, neck, torso, knees and ankles to simulate the loss of mobility that is a symptom of the disease.

Arthritis is characterised by pain and immobility and structural deterioration that occurs when a joint ("arthron" in Greek) becomes inflamed ("-itis").

Beanbags in pockets at the joints increase pressure during movement, causing pain.

There is even a simulation bunion - a painful deformity of the big toe joint - in one of the shoes. About nine million arthritis sufferers in the UK have similar symptoms, from mild to severe. Experts hope the suit can raise the profile of arthritis and show healthcare professionals and carers how it affects patients.

My ability to perform even simple tasks was impaired. Peeling potatoes was almost impossible. Pouring a cup of tea was messy. Sitting down on the sofa was a huge effort. But nothing could have prepared me for how awkward seemingly straightforward movements would be.

Velcro strips around the finger joints made it extremely hard for me to grip objects tightly, and after a while, simply trying to do so made me sore so unscrewing bottle lids was tricky.

One of many great tips provided by the National Rheumatoid Arthritis Society website suggests applying masking tape to the rims of jar lids to improve grip. I found picking up a full kettle was very uncomfortable as the finger joints are squeezed together. Having to then tilt the kettle to pour water into my mug pushed the sore fingers together even more and increased the pain further.

Although effective at reproducing joint immobility, the suit cannot get close to reproducing the severe pain arthritis sufferers endure. Pieces of red material were positioned – by arthritic individuals who helped develop the suit – in areas where pain is most often experienced.

Thankfully, when I fell over in the suit, somebody was on hand to help me. But that's not always the case for real sufferers. Dr. Mark Quinn, consultant rheumatologist at York Hospital, says, "Patients fall over and are left on the floor for hours, unable to get to their feet."

There are hundreds of types of arthritis – amongst the most common is rheumatoid arthritis, in which the immune system attacks joints and surrounding soft tissues causing inflammation, pain, stiffness, and ultimately permanent damage. This amounts to physical disfigurement and affects one in one hundred adults in the UK. It usually starts in the small joints of hands and feet, spreading to knees, hips, shoulders, elbows or spine. Onset occurs usually between the age of 40 and 60, but 12,000 sufferers are younger than 16.

Osteoarthritis is caused by erosion of the smooth cartilage covering the end of bones where they move against each other inside the joint. At least four million patients in the UK are affected, most of whom will be over 50.

It is not, as was once broadly accepted, due just to the natural processes of wear and tear, but also involves other factors such as age-related reduction in efficiency of joint repair; genetic predisposition and obesity.

Dr. Chris Scott-Batey, a GP registrar in primary care in Northumberland, sees many patients with osteoarthritis. He says, "Patients experience joint stiffness, limiting movement, accompanied by an aching pain when resting, becoming a sharp pain when the joint moves. The pain and stiffness are at their worst in the morning. Exercise strengthens the muscle and loosens the joint in the long term. And when large joints such as the hip or knee are affected, patients can only walk short distances. Rheumatoid arthritis often affects the smaller joints of the hands and feet, making it tricky to grip objects. The swelling can be disfiguring."

Treatment of rheumatoid arthritis has been revolutionised by a new class of antibodybased medicines - anti-TNFs (Tumour Necrosis Factor) - that suppresses inflammation.

Professor Bruce Kidd, consultant rheumatologist at St. Bartholomew's Hospital, London, says,

"These new treatments are a major step forward. Anti-TNF therapy blocks the key inflammatory agent called TNF-alpha, reducing the pain and stiffness and also the damage of auto-immune attack on the joint. Early findings suggest that this could eventually help effectively cure arthritis in some cases."

The simulation suit gave me a glimpse of living with arthritis. But I could take it off something not available to people with the real thing.

The suit is on loan to DIY specialist B&Q, which is using it to promote its "Can Do" range for those with impairments.

Dr Jack Lewis The Mail on Sunday **30th March 2008**

Information session – Benefits

We had a very successful morning with approximately 30 people in attendance Only three committee members were able to be there with me and I would like to say thank you to June, Joyce and Sheila for their help because I was really only fit enough to sit in my chair and make the introductions.

Denise gave a very good résumé of all the benefits available and contact details and was answering questions at the end from a long line of members.

Dorothy

The following are some amusing offerings from Ashley

Some guy bought a new fridge for his house. To get rid of his old fridge, he put it in his front vard and hung a sign on it saving: 'Free to good home. You want it, you take it.' For three days the fridge sat there without even one person looking twice at it. He eventually decided that people were too un-trusting of this deal. It looked to good to be true, so he changed the sign to read: 'Fridge for sale 50.' The next day someone stole it. Caution... They Walk Among Us!

One day I was walking down the beach with some friends when someone shouted 'Look at that dead bird!' Someone looked up at the sky and said...'where???' They Walk among us!!

My colleague and I were eating our lunch in our cafeteria, when we overheard one of the administrative assistants talking about the sunburn she got on her weekend drive to the beach. She drove down in a convertible, but 'didn't think she'd get sunburned because the car was moving'. They Walk Among Us!!!!

My sister has a lifesaving tool in her car it's designed to cut through a seat belt if she gets trapped She keeps it in the boot... They Walk Among Us!!!!!

I was hanging out with a friend when we saw a woman with a nose ring attached to an earring by a chain. My friend said, 'Wouldn't the chain rip out every time she turned her head?' I had to explain that a person's nose and ear remain the same distance apart no matter which way the head is turned...

They Walk Among Us!!!!!!!

While working at a pizza parlour I observed a man ordering a small pizza to go. He appeared to be alone and the cook asked him if he would like it cut into 4 pieces or 6. He thought about it for some time before responding. 'Just cut it into 4 pieces; I don't think I'm hungry enough to eat 6 pieces. Sadly, not only do they walk among us, they also reproduce!!!!

God & Satan

In the beginning God covered the earth with broccoli, cauliflower and spinach, with green, yellow and red vegetables of all kinds so Man and Woman would live long and healthy lives. Then using God's bountiful gifts, Satan created Dairy Ice Cream and Magnums, and Satan said, "You want hot fudge sauce with that?" And Man said, "Yes," and Woman said, "I'll have one too with chocolate chips." And lo, she gained 10 lbs.

And God created the healthy yoghurt, so that Woman might keep the figure that Man found so fair. And Satan brought forth white flour from the wheat and sugar from the cane, and combined them. And Woman went from size 12 to size 14.

So God said, "Try my fresh green salad." And Satan presented Blue Cheese dressing and garlic croutons on the side. And Man and Woman unfastened their belts following the repast. God then said, "I have sent you healthy vegetables and olive oil in which to cook them.

And Satan brought forth deep fried coconut king prawns, butter-dipped lobster chunks and chicken fried steak, so big that it needed it's own platter.

And Man's cholesterol went through the roof.

Then God brought forth the potato; naturally low in fat and brimming with potassium and good nutrition. And Satan peeled off the healthy skin and sliced the starchy centre into chips and deep fried them in animal fat, adding copious quantities of salt. And Man put on more pounds.

God then brought forth running shoes, so that his Children might lose those extra pounds. And Satan came forth with a Cable TV with remote control so Man would not have to toil changing the channels. And Man and Woman laughed and cried before the flickering light and started wearing jogging suits.

Then God gave lean beef so that Man might consume fewer calories and still satisfy his appetite. And Satan created McDonalds and the 99p double cheeseburger. Satan said, "You want fries with that?" and Man replied, "Yes, and supersize 'em." And Satan said, "It is good." And Man and Woman went into Cardiac Arrest. God sighed......and created quadruple bypass surgery. Satan chuckled and created the National Health Service.

Is It Urgent?

I awake unwell with swollen glands With fevered brow and sweaty hands I shake and shiver and cough and sneeze I sweat and flush and choke and wheeze I mutter and mumble and grunt and groan As I struggle downstairs to find the phone I first call work to let them know To the office today I will not show And then the doctor's line I dial A stern voice answers in a while "What name"? Is the curt response? An appointment please I say at once Well is it urgent? She retorts Well I'm not dving just out of sorts You can see a doctor in three weeks time I hope to be better by then I chime Shall I book you an appointment then? No if I'm not better I'll call again. But I'll say to you without offence If I'm still ill in three weeks hence I'll eat my hat till I eat my fill For I will never ever have been so ill

<u>Not Fair</u>

Life is indeed grossly unfair Now I'm older and still have my wits I've finally got me head together And my body is now falling to bits

Berry, Berry

The doctor scratches his head And is almost struck dumb Why does his patient have A strawberry stuck up his bum The only answer is On a strawberry he must have sat Then he says "I'll give you some cream to put on that"

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