



WRSG Newsletter

WOLVERHAMPTON RHEUMATOLOGY SUPPORT GROUP

Charity No. 1041181

CARING IS SHARING

Issue Number 80

OCTOBER 2008

Editor:

Dorothy Darby

Telephone: 01902 654417

E-mail Dorothy.darby@blueyonder.co.uk

Web: www.wrsg.org.uk

Contents:

Announcements

Features

Poems

Information Session

We are having an information session on Tuesday 14th October at the Holly Bush, Penn Road Wolverhampton, from 2.00 to 4.00 p.m. The talk will be by members of the Fire Brigade from 2.00 to 3.00 p.m followed by afternoon tea, coffee and cakes. There will be no charge for this event.

I feel that I do not need to send out admission slips because there is no limit on the number who can attend.

Will you take it as for the AGM that as long as you have responded by 25th September your place is booked and I only need to know for the catering

Reminder

Birmingham Symphony Hall Carol Concert

Sunday 21st December 7.30 p.m

The cost of the concert and coach is £24 per person. We will leave Falkland Street Coach Station at 6.00 p.m.

Cheques payable to the WRSG must be received by 1st October.

To book places please ring Sheila Fardoe between 4.00 and 6.00 p.m. only please

WRSG Annual General Meeting

The WRSG AGM was held on the evening of Monday 1st September at the Holly Bush 494 Penn Road, Penn Wolverhampton We provided a buffet and held a raffle. The weather was atrocious but we still had a good attendance.

We had very interesting speeches from Cheryl Etchells, Director of Nursing and Midwifery at New Cross and from our President Dr. Paul Newton, Consultant Rheumatologist.

We were also pleased to welcome Ken Purchase MP and Rob Marris MP The committee presented me with a lovely flower arrangement.

The minutes of the AGM, the Accounts and the Chair/Secretary's report will be included with the November newsletter after they have been agreed at our committee meeting in October.

Christmas coffee Morning

We will be holding a Christmas coffee morning with tea, coffee, squash and mince pies on Monday 15th December from 10.30 am to 12.30 pm at the Holly Bush, Penn Road Wolverhampton

We will have a raffle and Bring and Buy sales table. Jessica and Jack have given me lots of their outgrown soft toys because they say we are a "good charity" and the other things for sale are mounting up! We are short of raffle prizes though.

Can you help please?



Allergies

I know this is going to sound awfully ungrateful but I don't seem to be able to get my point across any other way.

I have chaired the WRSG Annual General Meeting for seven consecutive years now. At the end of the meeting the "Thanks" are given to the guest speakers and I have been presented with a gift to thank me for my work.

Apart from one year when I received wine and chocolates my lovely committee have presented me with flower arrangements or a bouquet of flowers and every year I have explained that cut flowers in the house make me ill.

This year Liz actually said "I know you don't like flowers but you are our chair and you have to have them" Oh dear I thought and I explained once again that it isn't that I don't like flowers they make me ill if I have them in the house.

Well they were very pretty and I put them at the far end of my dining room and closed the dividing doors so that I was sitting as far away from them as possible.

I tolerated them on Tuesday and Wednesday but by 6.00 p.m. on the Thursday my nose was itching, my eyes were sore and my breathing was laboured. I rang Kath and asked her to fetch them round to her house which she did straight away and I went to bed but I didn't get much sleep that night.

On previous occasions I have put them outside on the patio table and looked at them through the window but the weather was atrocious and they wouldn't have survived for long which would have been a complete waste of money.

As I said I know this sounds ungrateful but if I am chairing the AGM 2009 I would really be quite happy if someone just said "Thank you for a job well done" rather than coming home with something to worry about

With sincere best wishes to the committee
Dorothy

WRSG beginnings

The day after the AGM out of the blue I had a half an hour telephone call from Carol Boneham one of our founder members.

Carol was in New Cross and we chatted, funnily enough not about the WRSG or Rheumatology but about our families as Carol has a little grandson now.

I and the present committee do not run the WRSG the same way as Carol and Diane Evans did. I like to think we provide a camaraderie and support like an extended family and that we are there to help and advise members when they need us whilst giving them a good social life if they wish to join in.

Way back in 1994 when Carol and Diane founded the WRSG it was mainly because Wolverhampton had a contract with the Dudley group of hospitals and our services were provided at Dudley Guest hospital. Carol and Diane recognised the need for the inpatient beds and services to be provided in Wolverhampton and campaigned to that end whilst also proving support to members. Brenda, our WRSG poet was also one of the founder members.

At the same time I was campaigning through the Community Health Council with the same aim.

I don't think things are perfect in Rheumatology and I get confused about the in-patient beds but I think we are pretty well funded for our drugs etc.

Carol has invited me to visit her which I will do. Carol and Diane and Peter Evans are still members of the WRSG and I don't think it does any harm to remind ourselves of how the WRSG began and how we have progressed over the years.

Don't forget that if you encounter any problems in Rheumatology you can contact our patient representative Pat Jones and you will get sound advice!

In the September newsletter I sent my condolences to our member Ann Griffiths on the death of her husband Nort.

Ann sent me a note enclosing the following poem written and read by Lisa her Granddaughter at her Granddad's funeral. I don't think Ann will mind me sharing it with you.

Missing You Already but Remembering you is Easy.

IN MEMORY OF NORTON GRIFFITHS
1920-2008 by his granddaughter Lisa Higgins

Missing you already but remembering you is easy.

Riding your bike down Stowheath lane
Sitting at the kitchen table, pen and
Black Country Bugle in your hand.
Chatting about this and that
With a cheeky grin and a twinkle in your eye

Missing you already but remembering you is easy.

Tending your garden and watching it grow.
Admiring those birds and naming each one.
Looking up at the midnight sky, towards
The stars and that big shiny moon

Missing you already but remembering you is easy.

Asking how's the children?
And when are we coming again.
You were always in our hearts and
That's where you will stay.
You're back on your doorstep Grandad
Waving us goodbye

Missing you already but remembering you is easy.
All our love always from your loving family xxx

A little irritation

It is funny the little things which annoy me.
When I was watching the Olympic Games I noticed how everyone was saying "very, very" and "really, really" "That time was really, really fast" and that was a very, very good lap etc. I am constantly on the listen and I get so annoyed. My computer agrees with me because when I have just typed very, very and really, really it tells me it is a repeated word and I should delete it!!! It is grammatically correct if you put a comma in between.
How pathetic is that to let something so incidental bother me. Grumpy old woman I think.
Dorothy

This Life Today

Listening to the news each day,
So depressing, nothing to raise a smile
Wars are rampant, people dying,
Life gets harder all the while.
Stabbing and shooting are now common place,
What, if anything can be done,
Life so precious is quickly wiped out,
When someone carries a knife or gun

People are struggling with rising prices,
Can things really get much worse?
Gas, electric and food prices rising,
Nothing much left in your purse.
People always in a hurry,
There is never time to sit and chat,
Have we lost forever the caring society?
That sustained us in the past

Loneliness too is all around us,
But if someone takes time to talk to you,
And when they show how they care,
It gives you hope anew.
So when your life seems really bad,
With problems that just won't end,
If you reach out to someone too,
That someone could become your friend.

Bren.

New Feet

If I won the pools or the lottery,
I wouldn't want some fabulous treat,
No big car or exotic holiday abroad,
I would buy me a new pair of feet.
And if I won the X factor,
And was the toast of all the lands,
I would pay a brilliant Harley Street surgeon,
To give me a new pair of hands

I'm sure one day it could be possible,
As we live in a high tech age,
Perhaps then it would start a new fashion,
That might end up all the rage.
So until these things are possible,
I will just have to struggle on and cope,
And make the best of what I have,
But I can always live in hope.

Bren



I have been reading some personal stories from people with arthritis on the internet. This story is actually from 2000 but it made me think of what a long way the treatment of particularly rheumatoid arthritis has progressed in the last few years with the introduction of the anti TNF drugs. However I think most people diagnosed with RA will relate to Kenny's experience.

Arthritis from Boy to Man

This is my story of how I was told I had Arthritis through to the present day. The reason I am writing this story is to show people that we do not have to give in to the disease.

Back in the good old days when pain was a clip around the ear from your parents and arthritis had not yet reared its ugly head. I was a teenager who was already working and had done so since the age of ten with weekend jobs and such.

Not a care in the world did I have but in 1985 I started going to a gym and weight training. Not so long after I had made myself all beautiful for the ladies I woke up one morning with pneumonia. I did not know at the time what I had but I could not move. My arms were locked at the shoulders my legs did not even feel like they were there. But I do remember feeling frightened as I could not do anything, I had a fever of one hundred and four and my head was spinning around.

My Mother came into my bedroom to wake me for work but she found me in a right old state. She got my dad and they took me across the road to the local doctor. I will never forget that day as it was the beginning of a long and troubled road.

My doctor had diagnosed pneumonia but also Osteoarthritis which was why I could not move anything. He sat behind his little desk and stated that I would need some tests to see how bad things were, but I will never forget what he said next which was "You will probably be in a wheel chair by the time you are thirty". I gave him a right mouthful.

Who did he think he was to tell me I would be in a wheel chair I was at my peak fit as a fiddle.

I got treated for the pneumonia and went for my x-rays and bloods which showed that I did have arthritis, but only in my neck and shoulders.

Gradually things went from a stiff neck in the morning and evenings to my hands starting to hurt and swell and my hips becoming too painful to stand on for long.

I started working with my doctor on different medication to help with the pain that I was now starting to feel. Some painkillers worked. Some had to have anti-inflammatories added to help. Then came the side effects migraine, sickness, even internal bleeding at one point. I started going to the doctor about every five to six months with new problems and to keep on top of the side effects with even more drugs. I was a walking chemist.

At this point several years had passed and I had struggled to keep working, I ended up as a manager for a food production plant. In 1995 I was made redundant but walked straight into a similar job with a new company that had just opened.

At the same time my back took a turn for the worse and I had some real problems to deal with. In 1996 after a long year I had to go for a MRI scan which revealed that the vertebrae in my back had started to decay with the arthritis. I was sent to a neurological surgeon who offered to sever my nerves at the top of the spine in the neck, which in turn would mean that I would have no more pain. But the down side was that it would only last for three years and then I would have to have it done all over again. And as if that wasn't enough there was a fifty- percent chance that the op would paralyse me. I opted to fight through it and carry on with medication.

My mental health at this stage I think was starting to suffer. I was becoming more and more depressed but without knowing it. It was the people around me that noticed. My family and my friends and my life was being systematically taken away from me.

I went from a happy young man to a useless wreck. If it wasn't the pain it was the depression I was fighting, life was looking rather grim I can tell you.

My family were adapting more and more to my predicament but this made me feel like I was letting them all down.

Also being registered disabled later in the year was awful it felt like a death sentence was hanging over my head.

But as time went by I learned more and more about living with arthritis and my family were amazing when it came to support, as well as my friends who would do anything to help with shopping etc. Things slowly began to fall into place in about 1998-1999 the arthritis was being controlled to a certain degree with the medication that we had worked so hard to get right.

But life was beginning to get liveable once more and I started to occupy my mind with the computer and I started playing the Guitar. Odd instrument I know for an arthritic but it has worked well on my hands keeping them moving.

Just as I thought things were picking up for me and I was becoming less tense when I had to go to my doctor for a change of medication as they had started to let me down again. My usual doctor was on holiday so I had to see another one.

Now remember I have been treated for Osteoarthritis for the last fourteen years. The doctor went through all of my files and looked at me rather strangely and out of his mouth came the words "I think you have Rheumatoid arthritis."

Well you can imagine how that felt. He sent me for blood tests usual blood count bone profile rheumatoid factor and yes they came back with I have Rheumy.

The doctor is sending me to see the Rheumatologist to see if he can get me on a new plan for pain control. We will have to see what that brings.

But what I wanted you all to know is even after fourteen years of tests drugs prodding needles and the rest of the things we go through I will not give in to any Arthritis and we might not be able to cure it, but we can manage it and learn to live with it.

There will be those of you out there that have just been diagnosed and may think as I did that the end is near but please believe me you can get through it with a little help.

There is no need to shut yourself away from the facts. You are ill yes but you can still have a life and be happy. I am still learning but I am smiling as well and that's been a long time coming.

Kenny

Well as I said Kenny wrote that article in 2000 and I would love to know how he is now with the availability of the new drugs

Choose and Book hits 10 millionth booking landmark

More than 10 million electronic bookings have now been made using Choose and Book. This milestone comes just 12 months after the programme reached the five million bookings milestone in August 2007. As each day passes more and more patients are benefiting from Choose and Book. Patients are now able to book their appointments electronically at a place, date and time convenient to them anywhere in the country.

Patients have responded very positively to Choose and Book.

The role of Choose and Book in the NHS is becoming well established, with over 90 percent of GP practices having used the system over the past six weeks.

On average around 50 percent of all outpatient referrals to see a specialist go through Choose and Book.

All NHS Acute Trusts are now using Choose and Book, along with 91 per cent of all GP practices in England, which send over 105,000 referrals per week through the system.

Tuesday, 12 August 2008

Eastbourne
Ross to the Rescue!

I have explained that when I was discharged from New Cross my care was handed over to the District Nurses. The three ulcers on my leg healed well and the NHS Chiropody service have done a good job on my big toe nail.

I still had one problem; I had a small ulcer on the top of my foot which wouldn't heal because of the Lymphoedema (fluid retention).

I was sitting 24 hours a day in wet bandages and then I asked if I could use dressings and Mepore which I could change myself. That didn't stop the flow of water and I sat here in desperation thinking how can I go to Eastbourne in wet stockings and slippers?

Ross the Senior District Nursing Sister came on the Thursday before our holiday and she had thought of something else we could try. She had the new dressings delivered on Friday afternoon.

Success, the new dressing stopped the water and off I went to Eastbourne with a dry foot.

Eastbourne – The Holiday

We had a good journey down to Eastbourne without delays even on the M25.

I think it was a good choice of resort because many people on the holiday said they would like to go again.

A bonus was the weather. We had rain on Tuesday afternoon and drizzle on Thursday lunch time but otherwise warm sunshine.

Was I dreaming?

On Tuesday morning most people headed for the seafront where there were lots of benches on the promenade and very pretty gardens. We took advantage of a ride on the little Dotto train which takes you from one end of Eastbourne to the other. The journey takes two hours with a couple of stops on the way.

On Wednesday there was an organised trip to Hastings. Some chose to go to the shops and others took a walk along the front but it was rather bracing.

On Thursday some of us chose to go on the tour bus to Beachy Head. This was a pleasurable holiday with everyone able to do what they wanted, when they wanted.

There was very lively entertainment in the hotel on Tuesday and Thursday evenings and then we made our way home on Friday after a pleasant break.

Pension Credit

Further to our information session on benefits, I have received the following letter regarding pension credit which may be of interest to some of our members

Dear Mrs Darby,

I am writing to you regarding the changes that will be taking place from 6th October 2008 in relation to Pension Credit. You may have read in the Touchbase publication, March 2008 (edition 50) of the changes that have been announced.

Backdating of Pension Credit claims will be limited to three months, bringing it into line with other means-tested benefits. This will significantly cut the amount of personal information needed and speed up claims.

At the moment, arrears can be backdated for up to 12 months, but this requires pensioners to provide details of their circumstances for the past year. Backdating of Housing and Council Tax Benefit claims will also be limited to three months (for pensioners and working age customers). Although the changes will help to streamline the process, there could be customers who if they claim before 6th October 2008 may be entitled to backdating of 12 months, compared to three months if they claim after 6th October 2008.

The purpose of this letter is to make sure that everyone is aware of the changes as it may be beneficial to some customers to claim Pension Credit prior to 6th October 2008

If you are in contact with anyone you feel may be entitled to Pension Credit, and you would like Local Service to visit them, please contact me and I will make the necessary arrangements.

Should you require any further information, please do not hesitate to contact me.

Yours Faithfully

Karen Whitehouse

Telephone number 01902 435162

This is something else I found on the internet but I am sure it is something most of us experience at some time.

Serious long term effects of sleeping limbs, and any funny stories?

It happens to me quite often that I wake up to find that during the whole night, I have been lying on top of my arm (most often my left arm), thus cutting off the blood supply to the nerves (right?), resulting in the fact that the arm is "asleep" when I wake up. I "wake it back up" again (or more accurately, I increase the blood flow to it) by massaging and rubbing it until I can feel and move it again.

It never took me more than a minute and a half or so to do this, but still, the experience can be quite frightening or hilarious (depending on how seriously you take it). Sometimes, I actually worry about never regaining feeling in it again

(Cut me some slack, I'm still half asleep when this happens), as it flops around uselessly when I stand up, and feels really dead.

I was wondering, could there be any long term effects of your limbs being asleep for very long? Do you know any interesting facts about the phenomenon? Know any funny stories about sleeping limbs? Please share!

Answer 1

I have Rheumatoid Arthritis and as the muscle Atrophy, waste away due to the condition, nerves in my elbows are exposed. Therefore I am going through a phase where like you I wake to numb arms, elbow to hand. Usually I try not to do anything until I have warmed up. However last week I was the subject of a TV Documentary on RA, so had the Film Crew all day Thursday. I went to bed late, got up early Friday in a rush.

I fill the kettle by pouring a cup of water into the kettle, rather than holding the kettle under the tap.

Yes you have it, got the cup full of water, went to tip it into the kettle, only it kind of missed and landed, up the wall, down the kitchen cabinet, on the floor and I just laughed.

I was glad the film crew did not see this. Arthritic Mrs. Bean! Good Luck

Answer 2

My friend's leg goes to sleep all the time. It usually happens when she starts getting tired and she fell down the stairs once trying to run on it because she said it felt funny and ended up breaking her arm.

Answer 3

I don't know any facts or long term effects, but there have been a few times that I woke up and BOTH of my arms were dead! I couldn't move either one to massage them to get blood flowing again...all I could do is lay there like a helpless slug.

A Drunk and Arthritis

A drunken man who smelled like booze sat down on a bench next to a priest.

The man's tie was stained, his face was plastered with red lipstick, and a half-empty bottle of gin was sticking out of his torn coat pocket.

He opened his newspaper and began reading.

After a few minutes the man turned to the priest and asked, "Say Father, what causes arthritis?"

The priest replied, "My Son, it's caused by loose living; being with cheap, wicked women; too much alcohol; contempt for your fellow man; sleeping around with prostitutes; and lack of a bath."

The drunk muttered in response, "Well, I'll be," and returned to his paper.

The priest, thinking about what he had said, nudged the man and apologized. "I'm very sorry. I didn't mean to come on so strong. How long have you had arthritis?"

The drunk answered, "I don't have it, Father. I was just reading here that the Pope does."

GOD CREATED CHILDREN (AND IN THE PROCESS GRANDCHILDREN)

(from Pauline Callaghan)

To those of us who have children in our lives, whether they are our own, grandchildren, nieces, nephews, or students. here is something to make you chuckle. Whenever your children are out of control you can take comfort from the thought that even God's omnipotence did not extend to His own children.

After creating heaven and earth, God created Adam and Eve. And the first thing he said was 'DON'T!' 'Don't what?' Adam replied. 'Don't eat the forbidden fruit.' God said. "Forbidden fruit? We have forbidden fruit? Hey Eve we have forbidden fruit!" "No Way!" "Yes way!" "Do NOT eat the fruit" said God "Why" "Because I am your Father and I said so!" God replied, wondering why He hadn't stopped creation after making the elephants.

A few minutes later, God saw His children having an apple break and he was ticked! "Didn't I tell you not to eat the fruit?" God asked. "Uh huh," Adam replied. "Then why did you?" Said the Father "I don't know," said Eve. "She started it!" Adam said. "Did not!" "Did too!" "DID NOT!" Having had it with the two of them, God's punishment was that Adam and Eve should have children of their own. Thus the pattern was set and it has never changed. If you have persistently and lovingly tried to give children wisdom and they haven't taken it, don't be hard on yourself. If God had trouble raising children what makes you think it would be a piece of cake for you?

THINGS TO THINK ABOUT!

1. You spend the first two years of their life teaching them to walk and talk. Then you spend the next sixteen telling them to sit down and shut up.
2. Grandchildren are God's reward for not killing your own children
3. Mothers of teens now know why some animals eat their young
4. Children seldom misquote you. In fact, they usually repeat word for word what you shouldn't have said

5. The main purpose of holding children's parties is to remind yourself that there are children more awful than your own
6. We childproofed our homes, but they are still getting in.

ADVICE FOR THE DAY:

Be nice to your kids. They will choose your nursing home one day

AND FINALLY:

IF YOU HAVE A LOT OF TENSION AND YOU GET A HEADACHE, DO WHAT IT SAYS ON THE ASPIRIN BOTTLE: 'TAKE TWO ASPIRIN' AND 'KEEP AWAY FROM CHILDREN'!!!!!!

Section Two - First Day of School



Meet Pon →  ← & Zi Aren't They Cute!

Zi couldn't see her Dad for a while so she went back in to the school and told the teacher.

The teacher rang Zi's father but he didn't answer so she rang Zi's mother and she answered but she didn't sound too happy, she had the sniffles.

Zi's mother said "I will come straight away please tell Zi there is nothing wrong okay" And so she did.

Zi's mother came five minutes later in a hurry. She dropped Zi off at her Nan's and said "Your father is going away for um. a while, I'll be back" and she hurried off. Zi's mother didn't tell the truth. Zi's father had been in a car accident and is now dying in hospital unless they can make him better.

Find out whether he survives or not and if Zi finds out in Next Month's Newsletter!



By Jessica Darby

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

