# *WRSG Newsletter*

**WOLVERHAMPTON RHEUMATOLOGY SUPPORT GROUP** **Charity No. 1041181**

**CARING IS SHARING** **Issue Number 81** **NOVEMBER 2008**

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## Information Session

**We had an information session on Tuesday 14th October at the Holly Bush with a talk by Brian Pearson from the Fire Brigade. Approximately thirty people attended. They went away with a great deal of information and were able to register for a free home safety check**

## 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**
**The minutes of the AGM, the Accounts and the Chair/Secretary's report are included with this newsletter. Any comments/queries should be sent to me in writing.**

**At the AGM I asked if anyone to would like to join our committee. I am pleased to say that Trudy Bowen agreed to join us and was welcomed at our committee meeting on 14th October. See page 2**

## 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!**
**Thank you to the members who have responded to my appeal for raffle prizes. We should have a good selection for this Christmas coffee morning.**

**Booking forms are enclosed with this newsletter and we would like to see as many of you there as possible.**
**Please return your booking slips to me by 1st December so that we know how many to cater for.**

***Dorothy***

## CONGRATULATIONS

**Many of you will know Julie Stead as an Arthritis Care Challenging Arthritis Course Leader. Julie decided not to stay on the WRSG committee because of her heavy workload but is still a member and will continue to attend our events and man one of our three help lines.**
**Julie and Steve got married in September while they were on holiday and we send them our very best wishes.**
**Julie is now Mrs. Hibbs**

## My name is Trudy and I have RA

**I suppose that, on reflection, I had had signs and symptoms for many years but never made the connection. My first indication came in 1993 when my right knee became swollen and extremely painful, and when the swelling eventually subsided, was bent at a bit of an angle. Although very sore I managed to exercise it back into a workable shape and went on my merry way.**

**In 2002 (October) my school was subject to an Ofsted visit. Although we did extremely well those visits are always very stressful, particularly for the Headteacher. I felt a bit "under the weather" but then "that's Ofsted"**
**In November I went to Leeds for a conference one Friday evening and on the Saturday morning I experienced great difficulty in walking for no apparent reason other than I felt a bit "fluey". On the way home the next day my hands and feet began to swell and turn blue.**
**The rest, as they say, is history.**

**My GP introduced me to Dr. Newton who introduced me to sister Webb who introduced me to "the jab" and the rest of my medication.**
**What a relief! What I had has a name and "the jab" made me feel almost normal again albeit for a few weeks.**

**The rest of my story is, I suppose, much the same as your story. I kept on working until 2005 and then retired. I say retired but there was a part of my life that I hadn't really told many people about unless you count 10,000 plus electors in Bilston North and the City Council.**
**Yes, now I can admit it. I was a Councillor and not only that but in 2006 I was asked to be the Mayor of Wolverhampton. Needless to say my family and friends were divided about how advisable this was but my GP said it couldn't do any harm so I said yes. Little did I know what was to come**

**The role of Mayor lasts for two years, the first as Deputy (to give experience, deputise for the Mayor and thoroughly frighten you) and the second as Mayor.**

**Being the Mayor is a great honour, exhilarating and exhausting. So when you start out exhausted with your joints nagging it could have been impossible. But it wasn't because the Staff help tremendously and the warmth and humour of this great City and its' citizens got me through.**

**The first time I wore some of the priceless regalia, I looked down at it and realised there was a diamond missing. I looked about in the car for it but eventually had to admit to Andy, the driver that I'd lost a diamond. "Oh that's o.k." he laughed "it's been missing for ages." And that was only day two.**

**During the year I found that everyone was willing to help, although sometimes people struggled to understand the difficulties. When starting a particular road race I discovered that I was supposed to climb and stand on a podium for an hour. Dorothy took up my case explaining my predicament and asking for a chair for me to sit on between races and perhaps one or two other chairs for officials so that I didn't feel too stupid. The reply that she received was something like this. "There are only a few steps up to the podium which is made of scaffolding. The Mayor can hang on to the scaffolding" At least that's what I think it said.**

**There are so many tales to tell from hats, Mayoral and feathered to a tale of two Cathedrals and a scooter. The one I'll leave you with is how a friend seeking to be helpful, bought a spray which was supposed to ward off infections. I thought I would give it a try one day and sprayed it into my mouth. I didn't know they made several versions, one of which was a foaming hand wash. I may never live that one down as I emerged from the pit of the car foaming at the mouth.**

*Thanks for that Trudy. Can we look forward to your next instalment please?*
*Dorothy*

**As well as poems we have a very interesting article from Brenda Mullaney for this month's newsletter.**

## **The crunch doesn't mean don't munch.**

**Are you, like me really fed up of either reading about or watching on T V rich corpulent celebrity chefs telling us how to feed a family cheaply. Also how to keep warm now that we are on the verge of recession? Well the working class have, over the years always had hard times in our lives and got through. I am old enough to remember the Second World War although I was only a small child. Food was rationed to a bare minimum unless you had money and could buy food on the "black market."**

**Somehow my mother always managed to have a nourishing meal for my brother, my father and I. She seemed to conjure a meal out of almost anything. A few of dad's vegetables from the garden and a very small piece of stewing steak we would have a hot meal. Then for afters rhubarb and custard, Clothes were in short supply and like food you had to have coupons. Mom would cut up her old dresses and make me a skirt or a dress even.**

**All this and nightly bombing and going down the shelters most nights when the air raid sirens went. Then off to school as normal next morning clutching our gas masks.**

**My father was in the First World War so was too old for the second. He was assigned to ARP air raid duties. He was able to grow a few vegetables in the garden which came in handy for stews and casseroles if we could get some meat.**

**Later on in l962 I got married and we put a deposit on a house. A year later I had my first child, a boy, and two years later another boy. After that I didn't work (no nurseries then) and my husband's job was not highly paid at that time. After all the bills were paid we barely had anything left for food, clothes, gas and electricity but because I had learned as a child from my mom I coped by her example. There was no frozen food bought (too expensive) we had casseroles, stews with dumplings etc and we coped. My two sons now grown are over 6ft and well built.**

**When better times came and my husband's employment improved we were quite comfortable for a while. Then in the seventies we had the power cuts, the strikes and the three day week. Things once again were tough for a while but once again we coped.**

**There was mass unemployment thousands on the dole and the added stress of worrying if you would be made redundant causing many sleepless nights. We never could afford the luxury of central heating until much later so we had to depend on our gas fire in the lounge and a small heater in the bathroom. The lads would get undressed in front of the fire and then race upstairs to a bed I had pre warmed with a hot water bottle.**

**Obviously as we were much younger then we could move around to keep warm but for many older and disabled people this is very difficult and a major problem for them**

**What I am trying to say is some of these chefs have probably never known hardship in their lives. Maybe some have privileged backgrounds, but even the ones who came up the hard way now live comfortably and are able to afford a warm heated house and good food. People like myself who have a working class background and memories of really hard times have learned how to cope and do not need telling how to make a nourishing meal with a carrot and half a badger. (Sorry being facetious) so they can all go and ravish theirselves with some road kill and we will stick with our steak and kidney pud.**

***Bren***

## My recovery – Driving and a smile!

**At last after five and a half months I am pleased to say I am back on track. When I was admitted to New Cross hospital in April with arterial thrombosis (blood clots) in both groins and related circulation problems I didn't think it would take this long to get better.**

**As I have said in previous newsletters I have had a lot of help from Kath and Tony and Caroline, my neighbours and lots of visits and phone calls from other neighbours, family and friends. I also had a lot of help from the District Nurses and the Chiropody service but I can manage by myself again now.**

**The next thing I had to do was get behind the wheel of the car and drive! Best laid plans! One Tuesday morning I decided to have a go. I got my keys, locked the house and went to the car. I reset the seats and mirrors etc because the last person to drive it was the mechanic when I had it serviced and MOTd and he was a tall man. I adjusted everything, turned the key and nothing, a flat battery, not really surprising that.**

**I made a phone call and within fifteen minutes a "very nice man" from the AA arrived. I asked him to come in and explained that it wasn't just the car it was me. He said did I just want to charge the battery because we could leave the car running and lock it with the spare key, or did I want to drive it. I said I needed to drive it. He put the car on the road for me and waited until I drove off before he went. I forgot to indicate I forgot to put my seatbelt on and couldn't figure out what the bleeping noise was! I turned into the next street but when I indicated the windscreen wipers came on. I pulled up and thought come on Dorothy get your brain into gear as well as the car. I drove for forty minutes to charge the battery and by the time I came home I was fine apart from aching shoulders and arms. The next day I had a BCLSN committee meeting here and we had a seven hour power cut so I didn't drive that day.**

**On the Friday I had a Rheumatology appointment. My appointment wasn't until 11.00a.m but I went at 10.15 to get a parking space near to the department. I had to reverse into a space between two cars and although my parking was fine I was shaking like a leaf when I got out of the car and I really had lost my confidence. It is amazing how much an illness affects you mentally as well as physically.**

**I recently embarked on a course of Lymphoedema treatment on my right leg. It will be 50 years on 28th December that I had my road accident and no me and the leg are not having a party. The treatment entailed my leg being put in an airbag attached to a Lymphassist machine which has a pump action to help remove the swelling and get the leg into a better shape. Another part of the treatment is that your leg is heavily bandaged from toe to thigh for a period of time which I found very awkward living on my own. While I was bandaged I had an appointment in Dermatology for a small problem on my arm. When the nurse called my name I had a struggle to stand and walk and she asked if I had broken my foot. I explained that this treatment was something I wanted to try after 50 years and she said with a wry smile "Have you been on the waiting list for 50 years then?"**

**I don't know why but my hair has gone very frizzy while I have been ill. I tried several good conditioners, then I tried Brylcream and that was too greasy so Jack took it home. One of my neighbours got me some Vitapoint which has been around for many years. One Sunday morning I asked Jessica to rub some into my hair for me. She did it gently so as not to hurt me. Then she said "Nan at 64 does it really matter if your hair is frizzy" I replied "Well I am actually 68 and yes it matters very much. If you stop taking a pride in your appearance you might as well pack it in."**

**I know the last few newsletters have been a lot about me but please if you have a story to tell write to me and I will include it in a future newsletter.**

***Dorothy***

## WRSG Equipment Loan Service

**I borrowed a lightweight folding wheelchair from the WRSG for Ashley and Alison's wedding and for my trip to Westminster Abbey. We also took it to Eastbourne. I have now returned it but it proved to me how invaluable our WRSG Equipment loan service is. If you need help with equipment please ring Pat Jones on 01902 884495**

## A change of attitude I can understand.

**I have a friend and fellow member who has had many severe flare ups of her rheumatoid arthritis over the last three years and when we have been talking she has said how she has found peoples attitude towards her has changed. She used to meet her friends for coffee and shopping but when they rang she had to explain that she felt too ill to go out. She said their calls got less and less frequent and I said it was probably because they didn't know what to say or how they can help.**

**Before my illness this year I was the one ringing my friends and saying that an event was on and should we go and doing my share of the driving. My friends rang often during the five months of my illness and I suppose they knew I couldn't join in what they planned but eventually they stop including you. I am sure that this is because going out with someone when they are fragile is a worry. When I did go out apart from with Ashley and Alison, Greg, Ann and the children, Kath and Tony and Liz I felt a nuisance as I couldn't keep up!**
**As I have said previously I am now driving and walking well and I have my independence back. Now I will be able to speak with people on the helpline with an even greater understanding.**
**Life is a learning curve.**

## A Shared birthday and Caring is Sharing

**Liz Walker and I share a birthday on the 25th September. Liz is a couple of years younger than me. Over the years because of our Rheumatoid Arthritis, Arthritis Care and the WRSG we have become good friends. CARING IS SHARING**

**Liz was celebrating her birthday with a party with her very loving and close family. Ashley and Alison came from Wales the Saturday before my birthday and took me out to lunch. Greg, Ann and the children came on the Sunday with chocolates and a DVD of Phantom of the Opera.**
**Trudy Bowen came for the afternoon on my birthday. We didn't discuss our RA but we did talk quite a lot about how we cope.**
**CARING IS CHARING.**

**I had lots of phone calls and all was well until I carried a lever arch file upstairs at 8.00p.m. I am always dropping things and I dropped the file on my foot. Why when they have the entire floor to land on do things drop on your feet? Well it made a small hole in my foot but I am on Warfarrin and there was blood all over the place.**
**I managed to stop the bleeding.**
**The next morning I didn't feel well and I had the newsletters to do.**
**The team were not available this time.**
**I rang Liz for help and she came over.**
**She helped me clean up, made me a coffee and we set about the newsletters.**
**CARING IS SHARING**

**The next day my telephones were not working. Greg came over. He fixed the phones and he moved all the files from the high shelf in my office to a lower shelf in another room so that I don't drop them.**
**He did lots of other jobs in about half an hour which would have taken me all day.**
**CARING IS SHARING.**

**One of my friends says the newsletters should be called "Dorothy Darby's Disaster Diaries" but I do try to write about nice things too like when I went to Westminster Abbey.**

## Indulge me! - Grumpy old woman is back!

**Not only are people annoying me with really, really and very, very they are saying many, many, "basically" and "at the end of the day" all the time. Why?**
**Well I am really, really, very, very fed up in many, many ways and basically I would like this to stop because at the end of the day it is driving me mad! I am also getting on my own nerves because when anyone asks me to do anything for them I find myself saying "No problem" Why? I really must get a life!**

***Dorothy***

**On the Bright side**

**Children’s illustrator Sue Heap tells how a rationed drug put colour back in her life**

**There are a lot of higgledy-piggledy stairs in the award-winning children’s author and illustrator Sue Heap’s Oxfordshire cottage, hardly ideal for a woman who has suffered from rheumatoid arthritis for 15 years. During one particularly bad phase eight years ago, she could get downstairs only on her bottom.**

**“My knees hurt so much I couldn’t even walk 300 yards to the supermarket,” Sue Heap, a former winner of the Smarties Book Prize, remembers. “I couldn’t drive and, even if I made it to the cinema, I couldn’t get up afterwards without holding someone’s hand. I remember going out for dinner and having to use one hand to move the other to pick up a glass. To suddenly not be mobile was really alarming as I’d always been healthy and very active.”**

**Sue Heap, 53, is now free of symptoms thanks to “remarkable” drugs that have dramatically slowed the disease’s progress. For the past year she has injected herself with one of the three anti-TNF drugs that, in July, were severely rationed to NHS patients by the National Institute for Health and Clinical Excellence (NICE). It advised that RA patients who failed to respond to one type of anti-TNF drug should not be offered treatment with another.**
**Sue Heap is one of the fortunate 70 per cent who respond to the first anti-TNF drug they try. Other NHS patients have a 60 per cent chance of improvement with a second try, an option that might no longer be available.**

**Sue Heap is slim, bouncy and determined to look on the bright side. She has several projects on the go some on display in her studio with a fine view of the Cotswold’s, others in her garden shed.**
**These days the only obvious sign of RA is one swollen knuckle on her drawing hand. Yet before starting the anti-TNF drugs there were days when her hand and wrist were so painful that she had to wear a splint and could barely draw.**

**<u>The myths</u>...**

- **Rheumatoid arthritis is not an old people’s disease — it can develop in childhood, but the highest risk is between 35 and 55.**

- **Rheumatism is not the same as rheumatoid arthritis. The word rheumatism has no medical meaning, apart from a general description of aches and pains.**

**Her consultant also prescribed fortnightly injections of the anti-TN F drug, adalimumab, in combination with Methotrexate. Within weeks the inflammation had gone down and the pain had almost disappeared.**

**These days Sue Heap just gets the occasional “fiziing” in her hand if she does too much gardening or ironing.**

**There is little doubt that her sense of humour and natural optimism has helped her to cope; so has writing her illustrated diary. She tries not to think too much about the future, but when she received the first delivery of the anti-TN F drugs, her diary entry reads: “I was so relieved and happy. But when I hobbled downstairs to sign for them, I felt quite sad that this was my predicament for the rest of my life.”**

**She still has difficult moments, usually when she is tired. “I just hit a wall and feel a bit low. Then I have to stop. But on the whole I feel lucky to have had such wonderful care on the NHS and to have got the right drugs in time to keep the damage at bay.”**

## A spider in the bed

I woke in the night at 12.3O
Got up to close my door,
That's when I saw a very large spider,
Running across my bedroom floor

I went downstairs to get my new spider catcher,
You catch them then outside set them free,
But when I returned he ran under my bed.
Where next would that monster be.

I got into bed pulling the duvet over me,
Praying he wouldn't climb in my bed.
Hoping he wouldn't crawl on my feet,
Or worse still land on my head.

I spent the night tossing and turning,
I once read they can crawl in your ear,
My dreams were about man eating spiders,
The thoughts filled me with fear.

Morning came and after a fretful night,
I woke wondering where he could be,
I casually looked around,
There he was on the pillow next to me.

I had spent the night with the spider,
So I jumped up and opened my door,
And woke my son up to remove him,
Well that's what men are for.

*Bren*

## Orthotics

A proposal is currently being considered for an integrated orthotic service accessed by a single point of access that is a community-based service. The perceived benefits are felt to be:
quicker service access
triage to ensure appropriate treatment by clinician
less appointments across different systems
greater opportunity for "off the shelf" products that are felt to be appropriate by whole multi-disciplinary team.
I have now received the following update on the situation as mentioned in the September newsletter

“Dorothy the transfer of care board did approve the redesigned partway in principle and we are just recruiting to a project manager to deliver it”

## Never Forever

When I was ten I had a best friend,
Her name was Susan Jean,
I thought we would be friends forever
Till Becky came on the scene
At eighteen I had a boyfriend,
Who I thought was the one for me,
But teenage dreams are very often shattered,
And broken hearts don’t mend easily.

I thought when twenty two my fiancée would be forever,
Until that day he met my friend,
This time I had hoped it would be different,
Was this how it would always end.

In later life I thought you and I would stay together,
But fate again took a hand it seems,
And the pattern of my life continued,
And I was left with just my dreams.
Now I am older I remember as a child,
How I thought my parents would always stay,
But childhood hopes soon fade we know,
Too soon we learn the price we pay.

*Bren*

## Follow up – Nursing Care in New Cross

You may remember that in the letter from Matron Dodd and Matron Virk following my stay in hospital I was invited to attend a course on Care of the Elderly to share my views on my care.

I attended this course on the 8th October.
I began by saying that I was well aware that lives are saved everyday in New Cross Hospital and that I know they would have joined the nursing profession to help people.

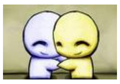
I then went on to give an account of my experience and concluded with the thought that I would hope that in future patients could be shown care and compassion as well as receiving their treatment.
I hope some good will come of it because it will then have been an hour well spent.

*Dorothy*

*This is a photograph of Liz Walker's granddaughter Isobel ready for her Halloween Party.*

*And one of Alison and Ashley ready for their Halloween Party*

## Section Three - First Day of School

**Meet Pon →  ← & Zi Aren't They Cute!**

**Zi's mother went to get Zi from her Nan's and to tell her that although her father had been in a car accident the doctors had saved his life and they could collect him from the hospital.**

**Pon and Zi stayed friends during their time at school**

*By Jessica Darby*

### NHS Centre to extend hours

**The opening hours at the Walk in Centre in the Phoenix Health Centre, Parkfield Road are to be extended and the new opening hours will be 10.00 a.m. to 7.00 p.m. during the week and 9.30 a.m. to 4.30 p.m. at weekends and Bank holidays**

**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**

*Remembrance day is even more significant than ever with our troops serving in Afghanistan and Iraq*

### Remembrance Day – Why the Poppy?

**Scarlet poppies (popaver rhoeas) grow naturally in conditions of disturbed earth throughout Western Europe.**

**The destruction brought by the Napoleonic wars of the early 19th Century transformed bare land into fields of blood red poppies, growing around the bodies of the fallen soldiers.**

**In late 1914, the fields of Northern France and Flanders were once again ripped open as the First World War raged through Europe's heart.**

**The significance of the poppy as a lasting memorial symbol to the fallen was realised by the Canadian surgeon John McCrae in his poem In Flanders Fields. The poppy came to represent the immeasurable sacrifice made by his comrades and quickly became a lasting memorial to those who died in the First World War and later conflicts.**

### Smile for you

**Smiling is infectious**
**You catch it like the flu**
**When someone smiled at me today**
**I started smiling too**
**I passed around the corner**
**And someone saw my grin**
**When he smiled I realised**
**I'd passed it on to him**
**I thought about that smile**
**Then realised it's worth**
**A single smile like mine**
**Could travel round the earth**
**So if you feel a smile begin**
**Don't leave it undetected**
**Let's start an epidemic quick**
**And get the world infected**