

WRSG Newsletter

WOLVERHAMPTON RHEUMATOLOGY SUPPORT GROUP

Charity No 1041181

CARING IS SHARING

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<u>Obituary</u>

Mr Phillip Harley (Phil)

It is with sadness that I have to inform you of the death of Phillip Harley one of our members on January 25th 2012. Our thoughts and prayers go to his wife Jenny and his devoted family.

Dates for your Diary

Please note that the dates for future coffee mornings will take account of bank holidays thus we will be having two coffee mornings in April 2012

Coffee Morning

Monday April 2nd 2012 10 30am – 12 30pm (Doors open at 10 00am)

Linden House, 211 Tettenhall Road, Wolverhampton. WV6 0DD

Demonstration by Boots No 7 make up and skin care (Invitations enclosed with this Newsletter)

Coffee Morning

Monday 30th April 2012 10 30am – 12 30pm (Doors open 10 00am)

Linden House 211 Tettenhall Road, Wolverhampton. WV6 0DD

Follow up from our Arthritis workshop.

Debbie Mitton (Clinical Nurse Specialist) Rheumatology, New Cross Hospital

Rheumatoid Arthritis and treatment innovations

(Invitations enclosed with this Newsletter)

Coffee Morning

Monday 11th June 2012 10 30am-12 30pm (Doors Open 10 00am)

Linden House 211, Tettenhall Road, Wolverhampton. WV6 0DD

Dentistry

(There will not be a coffee morning in July 2012 or August 2012. Viv Worrall is organising a day outing instead)

Group Outing

Monday 2nd July 2012

Weston-Super-Mare

Come and join us for a day at the seaside, don't forget your buckets and spades, sun tan lotion and sun hats, then we can hope for good weather!

The cost is ± 15 per person; a booking form is enclosed with this Newsletter giving you all the information.

The coach will drop off and pick up at a convenient place in Weston to avoid too much walking and wheelchairs can be taken on the coach.

In the interest of members who wish to take mobility scooters we have booked Hills coaches who have agreed that their drivers will handle 4 mobility scooters. Please could members who intend to take a scooter reserve their place as soon as possible so that we can assess the need for assistance?

I do hope as many of you as possible can join us for what should be a 'fun day out' so fill in your reservation form and send it back to Viv Worrall (her address is on the form) along with your cheque (made payable to the WRSG). Places will be on a first come first served basis and we hope to fill the coach.

Viv Worrall (Committee Member) WRSG) 01902 845706

Challenging Arthritis Course

The Challenging Arthritis Course sponsored by Midcounties Co-operative Community Fund will commence on Wednesday the 13th June 2012 1pm till 3 30pm. The Course will run for 6 weeks and will be held at Linden House, 211 Tettenhall Road, Wolverhampton. WV6 0DD

<u>Challenging Arthritis Comes to</u> <u>Wolverhampton</u>

Despite, or perhaps because of the prevalence of arthritis the disease is often dismissed by people as a natural part of the aging process.

But this assumption ignores the numerous ways that arthritis affects approx 1 in 5 of the UK population - not just elderly. But all ages. Fortunately help is at hand for WRSG members and residents of Wolverhampton with a free Challenging Arthritis Self Management course set up by the charity Arthritis Care and purchased by the WRSG.

The course is being run by two Arthritis Care members who themselves have to cope with arthritis so they have a vast experience on a personal level in dealing with the condition and are fully trained to deliver the material. Over the six week period participants will learn how to manage their arthritis more effectively by looking at many topics such as healthy eating, distraction techniques, relaxation, pain management, exercise and their relationship with health care professionals. The course provides support and understanding from being with other people with arthritis to share ideas and thoughts.

(Please contact Liz Walker 01902 563751) to book your place)

The course is being held at Linden House 211 Tettenhall Road, Wolverhampton. WV6 0DD.

Starting on Wednesday 13th June 2012 running for 6 weeks (1pm to 3 30pm) with a refreshment break. There is no cost to members and you will be provided with all material books handouts etc.

(Just to let you know Midcounties Co-operative Community Fund who have awarded £1500 to the WRSG to run the Challenging Arthritis Course has selected our group for monitoring purposes. Karen Argyle a representative of the Birmingham and Black Country Community Foundation attended our last coffee morning and met everyone. I will be emailing her our Newsletters so that she can follow our activities and learn more about our support group.)

Features

Breast Screening (A Message from Pat Jones)

Pat Jones a member of the WRSG committee has asked for this message to be included in the Newsletter. Pat is also a committee member of the Wolverhampton Breast Care Group Wolverhampton.

Breast Screening

I have learned to my amazement of the failure of women to take up this service. On an average screening day as low as 10 - 20women attend out of 60 invited women. What a waste of National Health Service resources! Twenty years ago breast screening probably saved my life. I felt no lumps and neither did any medical person but two tiny tumours were detected on routine breast screening. As I was caught so early I did not require chemotherapy or radiotherapy just surgery as the cancer had not reached my lymph glands.

I am reliably informed that the service is available to anyone with a disability, the scan can be done sitting down and the department can accommodate anyone using a wheelchair. The equipment used is 'state of the art' and the procedure is not nearly as uncomfortable as some would have you believe. The staff are great and are anxious that women take up this service.

I am urging all of you who do not take up this service to do so it really does save lives, so it is a case of 'use it or lose it'.

If anyone wishes to speak to me about the service or any related issues please do so.

Pat Jones (Committee member WRSG and Wolverhampton Breast Care Group)

01902 884495

WRSG Coffee Morning 6th February 2012 Feedback from Arthritis Workshop.

(Liz Walker)

I promised to give our members feedback from our coffee morning held on the 6th February 2012.

We organised a workshop for our members on 'Arthritis and what Arthritis meant to themselves as individuals. There were 6 groups who were able to talk to each other and exchange so much information and to give feedback to the larger group after their session.

It was very encouraging to observe the interaction that took place during the morning. There was distinctly a presence of expert patient with members who were diagnosed many years ago sharing their experience of self management of Arthritis with members who have are recently exposed to the Disease.

It was not surprising that each group reported very similar issues to each other about how their lives are affected. I have enumerated below a few of the issues which I am hoping to address in the future, starting with inviting **Debbie Mitton (Clinical Nurse Specialist Rheumatology) to our coffee morning on Monday 30th April 2012. Debbie has agreed to discuss Rheumatoid Arthritis and the changes over the years for treatment regimes.**

Issues Raised

We established that members attending the workshop day had the following types of Arthritis:

Osteoarthritis, Rheumatoid Arthritis Polymyalgia Rheumatica Cervical Spondylitis Fibromyalgia Sciatica Osteoporosis Psoriatic Arthritis The group overwhelmingly agreed that Arthritis had had a huge impact upon their lives and that of their families and friends.

The difficulties imposed upon each one of us in relation to everyday living such as dressing, showering, bathing, housework, cooking, mobility problems in getting out and about.

Pain, frustration, anxiety, depression, overwhelming fatigue, fear of the future,

Loss of independence, life changing impact upon work and social life. Impact upon family and carers.

Drug regimes and the impact of undesirable side effects.

Having to plan in advance your daily activities and accepting the limitations imposed upon you.

Positive Issues

I am happy to report that after taking everything stated above into account there was also a general feeling of positiveness in the room.

As you know I am committed to encouraging the concept of self care and self management. It is a testimony to those of our members who have taken this on board and are in control of managing their Arthritis.

As time goes on from when you are first diagnosed with what is a chronic disease process you learn different coping mechanisms and over time take control, accepting and accommodating different life styles and facing the future with confidence.

It goes without saying that I am also very committed to offering the Challenging Arthritis Course which does help you to develop self management skills and setting goals for the future allowing yourself to take control, so anyone wishing to attend the course please let me know in order to book your place. <u>Healthy Eating</u> The Following Eating Plate was featured in Katrina Maguire's talk given at our last coffee morning. The talk was very well received by our members. Thank you to Katrina for a very informative morning

The eat well plate below provides information on the type and amount of food to eat each day;

The eatwell plate



Use the eatwell plate to help you get the balance right. It shows how much of what you eat should come from each food group.



Click on the image above to visit the NHS website for more details.

For an indication on portion sizes, use the following as a guide;

- 1 apple, banana, pear, orange or other similar sized fruit
- 2 plums, Satsuma's, kiwi fruit or other similar sized fruit
- 1 large slice of melon or fresh pineapple
- 3 heaped tablespoons of vegetables
- 1 tablespoon of raisins or sultanas
- 1 cupful of grapes, cherries or berries
- 1 dessert bowl of salad
- 1 small glass (150ml) of pure fruit juice

In addition the following dietary recommendations will benefit your health and assist with weight management or loss.

- Eat more fruit and vegetables
- Eat regular meals to maintain energy levels
- Include a starchy carbohydrate with your meal- try and include those with low glycaemic index and choose wholegrain
- Cut down on the amount of fat you eat, especially saturated fat. Replace with monounsaturated fat but use sparingly e.g. olive oil/ rapeseed oil
- Include oily fish- aim for at least 2 portions/wk

- Choose lean portions of meat, try and include more beans and pulses
- Choose low fat dairy produce
- Limit intake of sugar and sugary foods
- Reduce salt intake- 6 g/day
- Drink alcohol in moderation (limiting this to 14 units/ week for women and21 units/ week for men)

Wolves Community Trust's Tackle Diabetes project provides education and lifestyle services for people Who have been diagnosed with diabetes, if you would like more information on this, contact Katrina Maguire, Diabetes Project Manager on 01902 687039 or email

katrinamaguire@wolvescommunitytrust.org.

SPONSORED WALK UP SNOWDON FOR THE WRSG



I would like to introduce our members to a very brave lady who will be attempting to walk up Snowdon to raise funds not only for our WRSG group but for our Rheumatology Department New cross and for the Arthritis Research Council.

EILEEN WOOLVERTON has Rheumatoid Arthritis (RA) and wants to do this walk so that she can give something back to the services that have helped to overcome her problems.

Hi There,

My name is Eileen Woolverton and I'd like to introduce myself.

Like you 1 have R.A. Everyone's journey through this disease will be different but I'm sure we all remember when our disease started, the way we reacted to our diagnosis and the changes we had to make in our life as the disease progressed. Each of us will have dealt with it differently, though there will also be common threads.

1 was diagnosed with RA when I was 49 and its onset was rapid and severe. 1 was lucky as my GP referred me immediately to Dr Ali, who I cannot praise enough. He and his nurse Helen were my first contacts with the Rheumatology Department and they were kind, understanding and positive. Various treatments were started and improvements made, though my disease, like many others, did not stabilize for quite some time. 1 always had problems with my feet though and could wear 3 different sized shoes in a day and still, if 1 went out in the evening, had to come home barefooted as my feet had swollen so much

Almost 3 years ago, as my RA had not stabilised enough I was offered a relatively new treatment which has transformed my life. I am now able to lead a normal life, something which had been impossible for the previous 10 years. I am determined to take this opportunity to do those things, while I am well, which I thought 1 would never be able to do again and to also try some new activities.

I have long wanted to play the clarinet and started lessons two years ago. (I'm pretty awful but 1 enjoy it and am improving or so my kind teacher says!) This is something I could not envisage doing when I was really poorly with swollen joints in my hand, 1 also wanted to go to Norway to walk in the Norwegian Fjords and see the midnight sun - it rises and sets at the same time in different parts of the sky fantastic. I was lucky enough to be able to do this two years ago and the experience was only made possible by the excellent treatment I have received from the Rheumatology Department in New Cross.

I recently decided I would like to give something back to the people who had helped me so much and thought I would like to do a sponsored walk - seems appropriate since I couldn't walk 100 meters when my problems first started and even walking on a carpet felt like walking on a thousand pebbles.

My challenge for this year is to walk up Snowdon to raise as much money as possible for the Rheumatology Department, WRSG and ARUK. I would be extremely grateful to anyone who could sponsor this walk, no matter how small a donation, as we will all ultimately benefit from it locally and nationally.

I am going to do this walk in May. The date will be decided by the weather as I do not think it wise or safe to walk during very wet weather. I will, however, let you know when we have done it through your newsletter. Also Liz has invited me to one of your coffee morning and if at all possible, after we have done our walk, I will come to see you

A friend, Gill, is walking with me who does not have problems and she has been acting as a trainer and motivator - we've been out every weekend since October to prepare and are making good progress now -we managed almost 10 miles last weekend.

I do hope you will be able to sponsor me. As you can imagine it would be an amazing achievement considering 13 years ago I could not walk upstairs but had to go up on my elbows and bottom!

Please find enclosed a sponsorship form for you to fill in if you feel you can make a contribution and thank you for taking the time to read this.

Kind Regards

Eileen Woolverton

Please find enclosed in this Newsletter the <u>Sponsorship Form</u> which is self explanatory. If you need any assistance please contact Liz

Walker. I will collect forms for the WRSG 01902 563751

Ring and Ride (A Message from the Chief Executive)

As I write this piece, we do not yet have a confirmed figure for our funding for 2012/13, although we have been advised that it will be in the region of £11m. If this figure is agreed by Centro, this will enable us to run a similar level of service to that being provided now.

Whilst I am relatively optimistic that we will receive a reasonable level of funding for next year, I am concerned that Centro is proposing that *'more robust* eligibility criteria be adopted for those who wish to use the service. Centro proposes that access to the service in future should be through meeting either automatic or non-automatic assessment criteria administered by Centro. The automatic eligibility would be linked to an externally assessed or demonstrable condition, and nonautomatic assessment would be through a questionnaire. In more detail, the proposed eligibility criteria are:

Automatic Eligibility (with supporting evidence being required)

- In receipt of Higher Rate Mobility component of DLA (certificate of benefit award); or
- In receipt of Higher Rate Attendance Allowance (certificate of benefit award); or
- Registered blind or partially sighted (BD8)
- or CVI); or
- In receipt of War Pension Mobility Supplement (letter of award); or
- Be over 85 years of age (Birth Certificate).

Non-Automatic Eligibility Assessment Self completion of a questionnaire, which may include requesting further details relating to requirements such as:

- Any documents relating to medical conditions, including copies of prescriptions.
- Confirmation of any other benefits received linked to mobility.

 Confirmation of mobility problem from medical and/or social practitioners.

Centro proposes to establish an appeals process to allow those turned down initially to appeal against the decision.

Consultation

There has to be a consultation in which all current users of the service, and other stakeholders will be involved, and the documents will be distributed to you by Centro very shortly. My concern is that the proposed criteria are very much based on a 'medical model¹ of disability, whereas the Ring and Ride service has previously relied in the 'social model', believing that it is the *needs* of each individual that is paramount. When you receive the consultation document, please take the opportunity to voice your opinion on whether you want the eligibility criteria to change, or you want it to stay as it is now.

Peter Maggs (Chief Executive)

In all of this I have hope The family I love help me to cope. Later on when my joints they replace There'll be no stopping me I'll be off, at a new pace.

Sheila wrote this poem many years ago and despite her many problems is a super role model for coping with her Arthritis. I know that her family joke about her scrap value with all of her replaced joints! Thank you Sheila.



Sheila Fardoe

<u>Poems</u> Arthritis by Sheila Fardoe

For twelve years I've had your hand to hold Not yet fifty, but already feel old. My days feel full of struggle As through life's chores I juggle. Things I can't do would fill a book Sometimes I feel down on my luck.

The hurt I feel, as you rush past to fill your day. I know I'm slow and get in the way. I know that you wish me no ill But it makes me feel right over the hill.

The stairs feel like a mountain to scale As I haul myself up holding the rail. I rattle with all the pills I take daily to cure my ills.

A day without pain, what bliss I wonder why my life's like this. I think it's all in the luck of the draw And I know I pulled the short straw. Thank you for taking time to read this edition of our Newsletter. I look forward to seeing you at the Coffee mornings.

Best Wishes to all our members

Liz Walker (Chairperson WRSG)

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