



WRSO Newsletter

WOLVERHAMPTON RHEUMATOLOGY SUPPORT GROUP

Charity No 1041181

CARING IS SHARING

Issue Number 106

October 2012

Editor Liz Walker 01902 563751

E Mail lizwalker_wrsg@hotmail.com

Minutes of the AGM held 14 09 2012

Linden House

PRESENT

Dr P Newton (President)
Liz Walker (in the chair)
Joyce Knibbs (Vice chair)
Eileen Woolverton
Viv Worrall
Kath Sankey (Treasurer)
Bhagwant Sachdeva
Jan Simpson
Eileen Woolverton (Guest Speaker)

1. Apologies

Sheila Fardoe; Dr Dixey; Paul Uppal,MP;
Debbie Mitten; Rob Marris; Utilda
Macfarlane Muriel Bailey; Nat Poonit; Pat
Jones; Balbir Rai; Silvia Horton; Reg Jones;
Mary and Ken Mannion;

Liz Walker; Chairperson, opened the meeting by welcoming everyone and Guests speakers; Dr Newton, President of WRSO and Eileen Woolverton who raised funds walking to the top of Snowden.

Liz introduced committee members on the top table and advised that the minutes from the Minutes of the AGM meeting held October 2011 had been agreed by the committee as a true record and that a copy was held if anyone wished to view them. There were no matters arising.

2. Re Election of Committee 2012 – 2013

All committee members have agreed to be re-elected for a further 12 months. This once proposed by Julie Hibbs and seconded by Pauline McDougal;

Liz Walker
Chairperson/Newsletter Editor

Joyce Knibbs	Vice /Chair/Holidays/Outings/Information Sessions
Kath Sankey	Treasurer
Sheila Fardoe	Outings
Pat Jones	Equipment Officer/Patient Representative
Bhagwant Sachdeva	Committee Member
Balbir Rai	Committee Member

Viv Worrall
Information Sessions/Outings/Holidays

Jan Simpson

Secretary

3. Chairperson Report (Liz Walker)

It is with pleasure that I return again this year to present the Chairpersons report for the WRSG. I am also happy to report that for another year the group remains very healthy and active, continuing to flourish with over 170 members enjoying the benefits that stem from the original concept of supporting Wolverhampton residents who have Arthritis.

Whilst preparing to write this report I have again revisited the original broad objectives of the WRSG and whilst reflecting upon the past year I can report that the group are achieving them all and in some cases excelling due to the hard work and commitment from our members and committee.

The Wolverhampton Rheumatology Support Group (WRSG) was founded in 1993 with Carol Boneham and Diane Evans as founder Chairperson and Vice Chairperson with Doctor Paul Newton as our President. We have had 19 years of experience now but our original objectives remain the same.

Even after 19 years despite, or perhaps because of the prevalence of Arthritis the disease is often dismissed by people as a natural part of the ageing process. But this assumption ignores the numerous ways that Arthritis affects approximately 1 in 5 of the UK population. Not just the elderly but all age groups. Over the past 19 years we have witnessed revolutionary progress with the management and treatment of Arthritis changing the face of Rheumatology inpatient and outpatient profiles significantly. Only a few years ago inpatient hospital numbers were high, today treatment is predominately as an outpatient or day care.

Despite the progress in the treatment and management of Arthritis the multi faceted effects of Arthritis upon the individual sadly

remain the same, by this I mean life changing effects such as pain, depression, anxiety, problems with mobility and loss self worth.

This is why the WRSG's initial objectives remain so important and that the group work closely with Health, Social and Voluntary Services to provide support to our members and to assist them throughout their journey of coping with the effects of Arthritis.

Objective: 'To support our members'

Supporting WRSG members is our main objective. We continue to work hard in order to meet this, the telephone help line is manned by Pat Jones and myself. All calls are confidential and as far as possible we are able to refer members to the appropriate services for assistance. We continue to work closely with Health, Social and Voluntary sectors and are grateful for their continuing support.

During this year the group have continued with the 'Buddy Scheme' which doesn't replace the help line but has proved to enhance this service. A Policy Statement for the Buddy Scheme was approved in November 2010. The scheme is constantly reviewed and I am pleased to report that it is working very effectively.

Our membership numbers have reached over 170; I am pleased to report that almost half of our membership are able to attend our coffee mornings and social events. Having face to face contact with our members is without doubt so much better and encourages positive interaction, sharing of experiences and drawing strength from each other. For those members who are unable for whatever reason to attend our coffee mornings and social events telephone contact, e mails, texting and the WRSG web site all play an important part in communicating with our members. We haven't really explored the possibility of using social network sites, twitter,

face book etc but I suppose we should really move with the times and certainly would welcome our members' views regarding this.

Objective: 'To facilitate Education and Information - Challenging Arthritis Course

During this year we secured funding through a grant from the Midcounties Co-operative Community Foundation Fund for £1500. Our application was approved to purchase a Challenging Arthritis Course from Arthritis Care UK. The course was offered to our members and commenced in June 2012.

The course was held at Linden House and 14 of our members attended. The course provided support and understanding from being with people with Arthritis forming relationships with Health care Professionals and sharing ideas, experiences and thoughts.

Our thanks go to Julie Hibbs and her colleague who managed the course. I have had very positive feedback as to the value of the course and the benefits members gained from having a greater understanding of their Arthritis and how to manage their Arthritis more effectively.

In the next twelve months although the cost is prohibitive we will be looking into funding for another Challenging Arthritis Course. As you all know I am convinced that a specific chronic disease self management course i.e.: Challenging Arthritis is better suited to our needs rather than a generic chronic disease programme.

Wolverhampton City Primary Care Trust do fund the Expert Patient Programme which is largely based upon the same concepts of the original Challenging Arthritis Course but offered as a generic chronic disease self management course.

The programme is very similar and addresses the same issues such as pain management, distraction techniques, relaxation, exercise, healthy eating etc. The course runs for 6 weeks for two and a half hours per week and will be free to our group. I will update our members with how we intend to proceed.

Information Sessions

During 2011/2012 we have organised several sessions to inform our members about issues relating to their Arthritis.

November 2011 Mary Shipway gave a talk on 'Indian Head Massage' which was very well received as always by our members.

February 2012 The group held an Arthritis Workshop. Members were invited to share their experiences and thoughts on what Arthritis meant to them as individuals. There were six groups who were able to talk to each other and exchange views and experiences and then feed back to the larger group.

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

It was not surprising that each group reported very similar issues to each other about how their lives have been affected. I have enumerated below a few of the issues which we have already started to address at our coffee mornings

Issues Raised

We established that members attending the workshop 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 and problems with mobility. Pain, frustration, anxiety, depression, overwhelming fatigue and fear of the future. Loss of independence, life changing impact upon work and social life and 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. In the meantime speakers were invited to address the issues raised from the workshop at our monthly coffee mornings.

March 2012 We had a presentation from Katrina Maguire (Wolverhampton Community Trust) on Diet and Arthritis

April 2012 Barry Picken (Chairman Wolverhampton Royal Hospital Trust) on Changes to the Health Service

June 2012 Pat Gutteridge (Wolverhampton Primary Care Trust) Arthritis and Dental Health

June 2012 Challenging Arthritis Course

September 2012 Debbie Mitton (Senior Clinical Nurse Specialist Rheumatology) Rheumatoid Arthritis

October 2012 We can look forward to another talk by Mary Shipway who will be presenting 'Reiki' another alternative therapy.

WRSB Newsletter.

The bi monthly WRSB Newsletter is an important vehicle of communication for our members. It is however costly to sustain. This year costs reached over £900. The committee are grateful for donations to the group that allow us to continue with the Newsletter; this year Waitrose donated £350 which we have used towards the cost of printing etc. I have cut down on some postal costs by E mailing the Newsletter to those members who are agreeable. We will however continue to mail the Newsletter to all other members. Kath Sankey and I are in the process of applying for a grant from Wolverhampton Wanderers to help with the ongoing costs for 2012/2013.

I am indebted to Martin Peake who has kindly taken responsibility of managing the WRSB website www.wrsb.org.uk Martin updates the site with the Home page and contact details, Newsletter, invitations to coffee mornings, information sessions, future holidays and trips, he has also included links and information regarding Arthritis. This is a huge technological aspect of the WRSB that none of us are qualified to do, thank you so much Martin.

Thanks are also due to our professional colleagues for articles included in the Newsletter:

Sister Norma Rowlands for her article on Osteoporosis - Mary Shipway for her article on Indian Head Massage - Sally Giles (Rheumatology Clinical Trials Nurse, Cannock Chase Hospital) for her article on the Clinical Trials Department) - Katrina Maguire (Wolves Community Trust) for her article on Healthy Eating - Pat Gutteridge (WPCT) for her talk on Dental Health - Barry Picken (Chairman WRHT) for his talk on Changes to Health Services

Objective: 'Sharing is Caring Social Network'

Our monthly coffee mornings held here at Linden House on the first Monday of every month are becoming more and more popular. Thanks to Joyce Knibbs who is responsible for booking guest speakers and liaising with Linden House we hope we are able to facilitate for all of our members interests.

Our social calendar this past year included a Turkey and Tinsel holiday at Bodelwyddan Castle North Wales December last year.

A Christmas Meal at Linden House on the 5th December 2011. A record number of 84 members attended this lovely meal.

Christmas Carol Concert at the Symphony Hall Birmingham on the 22nd December 2011

A holiday to Babbacombe with 21 members enjoying themselves in May 2012 and a trip to Weston Super Mare in July 2012

Donations and Grants

We are so grateful for everyone who has financially supported the group. Monies raised from raffles, cake competitions and bring and buy sales do help with the running costs of our coffee mornings and other events. It means that we are able to maintain our membership fee at the same level of £5 for individual annual membership and £8 for family membership.

This past year we have been very fortunate to secure two major grants. - West Midland Co operative Grant of £1500 which we have used to fund the Challenging Arthritis Course in June of this year and Sports Relief Grant from the Birmingham & Black Country Community Foundation for £1000 which we are using to fund the next Twelve months coffee mornings for the hire of the venue and speaker fees.

Waitrose donation of £350 used to help fund the Newsletter costs - Eileen Woolverton (Snowdon Challenge) final figure to be confirmed.

Currently Kath Sankey and I are in the process of applying for a grant from the Wolves Charity Fund to assist with the costs of the Newsletter for next year.

In Conclusion

We have had a very busy but very rewarding year. May I take this opportunity to thank the people that are responsible in no small way for the success of our group. Thank you to our committee who have worked tirelessly this past year, Joyce Knibbs, Kath Sankey, Jan Simpson, Sheila Fardoe, Bhagwant Sachdeva, Viv Worrall, Balbir Rai and Pat Jones.

And finally thank you to our members who are so supportive of the WRSG and to Doctor Newton as our President for his support. - -

Liz Walker (Chairperson WRSG 2012)

3. Treasurers Report; Liz Walker on behalf of Kath Sankey

ANNUAL ACCOUNTS 01 JUNE 2011 – 31 MAY 2012

			Opening Balance 01 June 2011; £6819.07
INCOME	AMOUNT	TOTAL	BALANCE
Subs	742.00		
Donations	502.76		
Equipment	0.00		6819.07 b/forward
Grants	2500.00		
Fund Raising/outings	13073.01		16825.26
Sundries	7.49	16825.26	£23644.33
EXPENDITURE	AMOUNT	TOTAL	CLOSING BALANCE
Postage	482.22		31 MAY 2011
Stationary	103.91		
Link Line	0.00		
AGM	350.00		
Fund raising/Outings	12780.20		
Sundries	60.28		

Equipment	128.00		
Expenses	816.60		
Travel	0.00		
Photo Copy	431.22		
Education	1500.00	16649.43	£6,994.90

4. Equipment report; read out on behalf of Pat Jones.

Sorry I am not with you all but I'm in France having a holiday. I have now moved to Codsall and still unpacking boxes after five weeks.

Wheel chairs can now be stored at Gunstone Hall. There seems to be little demand these days for equipment. I can only surmise that the N.H.S supply is good, plus the many outlets for buying your own. Lloyd's chemists have a wide variety of equipment available for purchase as do many of the supermarkets; I'm sure you have all been impressed with the Para Olympics and the wheelchairs used by the athletes! Maybe there's a market in 'jazzing' up wheelchairs?

Best Wishes to all.

5. Joyce Knibbs, Vice Chair; Information Session and Holidays

This year has been quite busy. Our Tinsel and Turkey break at Bodelwyddan Castle was a really good holiday, helped along by a free bar!

We had a wonderful Christmas meal here at Linden House last year; hopefully the same venue will be booked again for this year. Our Christmas Carol concert at the Symphony Hall in Birmingham was good, approx. Forty members attended. However we shall not repeat this as we do our best to try something different each year.

May 2012 saw the group going to Sefton Hotel, Paignton, the Hotel was not to our standard. I think we will give that a miss next year.

Our Tinsel and Turkey this year will be at Bembridge Hotel, Isle of Wight – 19 to 24th November. This holiday also includes a free bar in the evenings. The cost of this is £285.00, which includes two day trips.

The information sessions / coffee mornings are proving to be very popular with everyone. Suggestions & ideas for these are always welcome.

For our group holiday next year we are looking at a choice between a cruise, or a holiday in Spain; this will be discussed and decided at a future meeting.

6. Viv Worrall, Outings and Attendance of Coffee Mornings; 2011 – 2012

Two trips have taken place in the last financial year. The first was a ride over Cannock Chase and lunch at Mill Farm Carvery, 49 people came on this trip. The lunch was very enjoyable and after lunch we went to Wolsey Bridge Gardens for a bit of retail therapy, which is always good!

The second trip was on the 7 June to Weston Super Mare, thinking it would be a lovely day for weather in July – How wrong can you be....knowing how our summer has been this year, no need to guess it poured with rain all day. This didn't dampen our spirits, most of us decided we might as well get wet inside instead of out and went for a coffee, followed by lunch and of course the usual glass of wine or two. The centre of the new pier for walking along is undercover, so it was possible to go to the end without getting wet and the coach was parked nearby. We returned home at 3.45 instead of 4.30 which suited everyone due to the weather conditions; so a good day was had by all. One thing the weather can never be worse than that

on future trips, it can only get better !!! The next trip we have organised is a visit to Trentham Gardens on the 17th October. There really is something for everyone there. A lovely easily accessible shopping village with plenty of eateries. Also a very large garden centre with cafe, restaurant and outside area. For those interested in the garden they are lovely and well worth a visit. Wheelchairs can be used from the entrance at no cost, however they do request you leave your keys as security until the wheelchair is returned. The charge for disabled and carers is £4.50 each, senior citizens £7.00, adults £8.20. There are seats available on the coach at the cost of £9.00. The shopping village and the garden centre is free. I would like to thank members for their prompt timekeeping on outings, it is really helpful when you have coaches waiting and a timetable to keep to. Thank you all.

The average attendance for the coffee mornings 2011 / 2012 is 51. This exceeds our previous year by 10. Again thank you for your support.

7. Bhagwant Sachdeva; committee member who introduces WRSG to the Asian community

Good afternoon friends, I first met Liz Walker through a friend of hers who worked with me at Compton Hospice. Liz soon suggested I join WRSG and become a committee member responsible for introducing Asian members to our Arthritis management Group, WRSG. Now when I go to Asian Group meetings, I explain where and how people with arthritis can get help and support on how to manage their condition. Many people have already benefitted from this information, which I explain in three different languages; Hindu, Punjabi and Gujarati. We now have 28 Asian members in WRSG, this is 18% of the 176 members. Thank you to all who join us.

8. Any Other Business - Liz Walker read out a letter from Reg Jones;

In his letter Reg advised;-

- a) Bus passes are safe and can be used on buses anywhere in England. In the West Midlands they can be used on the metro and on the trains going south, as far as Coventry.
- b) The 'Ring and Ride' service are talking about assessing individuals ability to use public transport. I.e. to use a bus instead of ring & ride. Reg pointed out that they could lose money, they advised that Centro funded ring and ride and it was Centro that wanted to bring about the changes in the service. If there are any changes they may come into being about April 2013.
- c) The Blue Badge system has made great changes for people with a badge ; anyone re-applying may have to go for a medical assessment. The application form is about 31 pages long.

Reg kindly said that if there are any changes made in any of the above he will keep the group advised.

9. Guest Speakers

Dr Newton (Consultant Rheumatologist/President WRSG;

Dr Newton stated that he was pleased to hear the group had 176 members. Quite an achievement after 20 years to keep an activity going and indeed flourishing is a sobering thought as the years go by. There have been enormous changes of medical treatment

throughout with many new treatments for all forms of arthritis. In the past surgery was the answer for osteoarthritis, however this could all change thanks to new treatments becoming available. It is a great revelation of how changes have occurred over the years and still are, with more to come. It is nice to be in an environment where things are happening. Changes to the health service, treatment, Society and the welfare of people are all changing for the good, things like the Disability Discrimination Act. However there are changes to be cautious about, especially younger people, the changes to the benefit system are frightening. It is being made difficult to access. We all agree that it needs reforming, but they are blundering and penalising genuine people. It is difficult to assess 1000 of people correctly for their disability. It is difficult to get help from Social Services, it seems their decision making is about money and budgets being reduced. These are areas we must keep an eye on as outcomes may be unfair

On a different note - The challenging Arthritis Course in his opinion is to help sufferers to get on with their lives. A big thank you to WRSG for bringing this opportunity into member's lives and for assisting people to get on with managing their arthritis.

Eileen Woolverton – Walk up Snowdon.

Thanks to Liz for inviting me this afternoon and for the excellent write up in your newsletter. I would also like to thank the hospital workers. I feel lucky to have New Cross as my hospital, for the help offered, the new medication gave me my life back. It gave tremendous relief and help for my condition. I started to get better and thought of ways I could give something back to the people who had helped me. I could not walk at all well when I was poorly, walking was something I had previously enjoyed, so I decided to walk up Snowden, something I had done about 29 years ago. As the idea developed,

during the winter months I walked most weekends in training, with a friend, who supported and helped me do this walk before deciding on 12 May 2012. We checked the weather for that day. When it came round we got up early and had a wonderful day. It took 3 hours, we went up on the East side and down the West. Down was the hardest on the knees. However we had a good time and it was a great achievement. In total we raised £850. I shall be donating part of the money to the Rheumatology Department, about £400 to WRSG and the remainder to Arthritis research. I would especially like to thank Dr Ali, who was the first Doctor at New Cross I saw about my condition, and Ellen who worked for him. - Sister Frazer, Sister Hughes and Dr Dixey.

Liz Walker – presented Challenging Arthritis certificates to people who had not been able to receive them on the course.

Before closing the meeting Liz was presented with a gift as a token of gratitude for all the hard work and time she puts into the group.

Close of Meeting

Liz Walker (Chairperson WRSG)

Please note matters arising from the minutes please forward to our secretary Jan Simpson 01902 601967