

Cross-Party Group Meeting: Arthritis and Musculoskeletal Conditions
Committee Room 4
Wednesday 14 June 2017
5.30pm-7.30pm

Convenor: Brian Whittle MSP
MSP members attending: Pauline McNeil MSP

Office of Brian Whittle MSP Grace.Crisp@parliament.scot
CPG secretariat: Anne Simpson ansimpson1954@outlook.com

Meeting Notes

1. Convenor Brian Whittle MSP (BW) welcomed all members
2. Apologies from Group Members: Rhoda Grant MSP, Alex-Cole Hamilton MSP, David Stewart MSP
3. Minutes of 1 March 2016 meeting approved

Proposed: Lorna Neil, Polymyalgia-Giant Cell Arteritis Scotland

Seconded: Angela Donaldson-Bruce, Arthritis Care Scotland

4. Matters arising

Re: the presentation on the impact of social deprivation and lifestyle on inflammatory arthritis – BW stated that this had fulfilled the context of the brief and he would be happy to correspond direct with any individual members if any further comment wished to be made.

5. Living and Working with Arthritis and Musculoskeletal Conditions

Three organisations highlighted the difficulties to maintain facing those having to cope with the various conditions and especially to be in employment and how powerful an influence it can be for people to describe their own experiences when calling for improvements in services and the workplace.

- **“State of the Nation” survey - Giving People a Voice**

Debbie Cook (DC), Chief Executive, National Ankylosing Spondylitis Society (NASS)

NASS undertook a UK wide survey in 2016-with 2000 respondents-149 from Scotland.

The survey revealed how pain, stiffness and particularly fatigue can dominate the lives of people with a diagnosis of Ankylosing Spondylitis, making living with the condition so difficult and depressing.

It can be a difficult and lengthy process to reach a diagnosis.

84% of Scottish patients are under the care of rheumatologists but there is a lack of specialists in Ankylosing Spondylitis.

The survey revealed that access and support to exercise, so important in the management of the condition, can be variable - only 55% seen by a physiotherapist. Access to hydrotherapy also varies with - for example - the Edinburgh branch of NASS facing threat of hydrotherapy sessions being withdrawn in recent years.

Worryingly 52% of respondents reported going to work when unwell.

As well as fast access to rheumatology during flares, NASS would like everyone to have their own care plan to help them manage their flares more effectively.

According to the survey currently only 8% of patients receive this.

- **The power of personal stories – influencing the UK Government White Paper on work, health and disability’.**

Phil Baker (PC), Director of Commissioned Services, National Rheumatoid Arthritis Society (NRAS)

PC described recent input by NRAS to the UK Government White Paper on work , health and disability and how personal stories were so vital in highlighting the difficulties faced when trying to keep in employment while living with a long term, musculoskeletal conditions such as rheumatoid arthritis.

The Disability employment gap is widening.

What a waste of human resources if so many people have to reduce, change or give up working.

Colleagues/middle managers not aware and supportive of how there can be good and bad days.

Support to reduce hours/work flexi-hours would be helpful.

People seeking work were faced with a lack of understanding by staff of the various conditions- not knowing the difference between rheumatoid arthritis and osteoarthritis for example. Job centres assumed people were only eligible / suitable for lower skilled/lower status work and offered roles inappropriate for their condition.

Depression is common.

- **Joint working, the impact of arthritis on everyday working life**

Angela Donaldson-Bruce, (ADB) Director, Arthritis Care Scotland(ACS)

ADB highlighted results of the *Arthritis and Work* 2016 survey by Arthritis Care Scotland and University of Glasgow.

10 million people in UK have Arthritis – almost 1m in Scotland with 200 types of arthritis.100, 000+ GP consultations each year for MSK conditions.7.5m working days lost each year. Arthritis can affect *any* age group.

81% respondents were in work when diagnosed but only 44% remained in work. 1in 3 people stopped working within 5 years - 50% within 10 years.81% said arthritis had a high / very high impact on work. 54% reduced their hours or changed their duties.4 out of 5 people reported feeling anxious or depressed due to their arthritis

***Arthritis: Emotions, Education, Employment and Me* Stacey Highfield, Arthritis Care Scotland**

Stacey’s personal story of being diagnosed with arthritis when a teenager and subsequently her struggles to continue education then employment indeed reflected all points raised by the 3 organisations.

[Meeting Break]

6. Questions, Comments and Discussion

BW interested in hearing about people managing long term conditions and their access to physical activity.

Real life stories were so important and would like to hear more.

Need to change outlook-health service needs to keep people (also managing a long term condition)well.

Preventative approach not easy.

Can we please hear about areas of good practice?

DC felt that the role of the physiotherapist was so important regardless of the condition- and also support in maintaining mental health when difficult to have timely access to any service and also to keep in work.

The NASS survey did not include Mental Health as a measure-would need a whole survey itself.

It was felt that rehabilitation had lost its way-only pockets of good practice despite integrated agenda.

A multidisciplinary team approach including occupational therapy would be best but variable in Scotland and depends on size of rheumatology service per health board area.

Lorna Neil(LN) felt that care plans useful - patient wants access to support in flare up-not necessarily doctor but their rheumatology nurse-how many are there in Scotland?

What are the waiting times for physiotherapy?

BW commented that he would want physiotherapy when needing it and not in a few months' time.

Gail Grant (GG)-proposed inviting Jeane Freeman MSP –Minister for Social Security-to a future CPG meeting.

7. Any other business

- Question from Group secretary Anne Simpson(AS) on behalf of Joan Kerr-individual member –who had been unable to attend in person

"The European Cross-border Healthcare Directive was transposed into law by Scottish Government in 2013. It allows people with a rare condition access to diagnosis/treatment in the European Economic Area that may not be available in their Health Board."

What measures would the Scottish Government take to continue this arrangement after Brexit? .

BW stated that as this was not a devolved matter he would write to the Westminster Government for a response.

- BW raised the possibility of a Group Reception in Parliament in 2018

There was generally some appetite for this by members

Focus and outcomes from the event to be agreed – AS will ask members for comment before next meeting on 13/9/17.

AS /GW to explore cost of an evening reception and identify possible funding sources to support the event.

8. Summary and Next Steps

BW thanked everyone for attending and reiterated the request to hear more personal stories and examples of good practice.

9. 2017 Programme - Save the Dates

Wednesday 13 September (including AGM), 17:30-19:30	
Promotion of bone health, primary and secondary prevention of osteoporosis, prevention of fragility fractures/Scotland	Dr Stephen Gallacher, Consultant Physician, NHS Greater Glasgow and Clyde
National MSK programme Update	Judith Reid, National Lead, MSK Programme, Scottish Government
Wednesday 8 November, 17:30pm-19:30pm	
Psoriatic Arthritis update and recent research	Dr Stefan Siebert, University of Glasgow and

	Consultant Rheumatologist, NHS Greater Glasgow and Clyde
Giant Cell Arteritis - fast track to diagnosis and treatment	Dr Jane Gibson, Consultant Rheumatologist, NHS Fife
Scottish Metrics for the Assessment of Rheumatoid Arthritis Treatment (SMART) - Update	Dr Ruth Richmond, Consultant Rheumatologist, NHS Borders and President, Scottish Society of Rheumatology
Summary of 2017 meetings, actions, next steps	

Attending

MSP

Brian Whittle MSP
Pauline McNeil MSP

Non MSP

Phil Baker	National Rheumatoid Arthritis Society
Stacey Highfield	Arthritis Care Scotland
Debbie Cook	Chief Executive, National Ankylosing Spondylitis Society
Angela Donaldson-Bruce	Director, Arthritis Care Scotland
Gail Grant	ABVIE Pharmaceuticals
Nicki Gray	Rheumatology Service, NHS Borders
Lorna Neill	Chair/Polymyalgia Rheumatica-Giant Cell Arteritis Scotland
John Paton	National Rheumatoid Arthritis Society

Apologies

Matt Barclay	Community Pharmacy Scotland
Murray Brown	NASS
Iain Macdonald	NASS
Fay Campbell	Rheumatology Nurse NHS Greater Glasgow and Clyde
Senga Cree	National Lead, Musculoskeletal Programme, NHS Scotland
Mayrine Fraser	National Osteoporosis Society
Karen Graham	Osteoporosis service, NHS Borders
Catherine Lees	NHS Lanarkshire
Margaret-Mary Gordon	Consultant Rheumatologist, NHS Greater Glasgow and Clyde
Gillian Howie	Strathclyde Lupus Group
Janice Johnson	Individual member
Angie Lloyd Jones	Strategic lead for OT and Re-ablement Scottish Borders
Sheila Macleod	NRAS
Bea Nicolson	Polymyalgia Rheumatica-Giant Cell Arteritis Scotland
Marion Read	Polymyalgia Rheumatica-Giant Cell Arteritis Scotland
Sheila Terry	NRAS