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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Gofal Arthritis

Response from: Arthritis Care

Introduction

This submission is in response to the Health, Social Care and Sport Committee (HSSSC) request for external organisations to help inform its Forward Work Programme.

We would like to recommend that the HSSSC look at arthritis related health care issues in Wales and opportunities to reduce the impact of the condition on individuals, families, communities and the wider economy.

Arthritis – a 21st century health care priority for Wales

With Wales's ageing population and the rise in obesity levels, the prevalence of arthritis is set to grow. It is estimated that 2010 prevalence levels will increase by 50% by 2030¹.

Arthritis can strike at any age. An estimated 480,000 people in Wales live with the condition, 10 million across the UK. Living with arthritis can mean experiencing pain day in, day out. It can mean waking to pain in the morning and falling asleep in pain at night. Arthritis can impact on all aspects of a person's life – from being able to perform activities of daily living that we otherwise take for granted, such as getting dressed or making a cup of tea, to family and social life as well as employment.

Pain is not visible; therefore, arthritis is often a hidden condition.

The tremendous impact of arthritis isn't restricted to individuals and their families. Arthritis is a leading cause of disability and work absence in Wales and has a huge impact on the NHS, social services and the wider economy. Musculoskeletal conditions account for 30% of GP consultations² and 42% of reported cases of work-related ill health³.

'It's the forgotten condition that no one thinks is important. It affects everything. It's exhausting, depressing and makes you feel angry and frustrated. It robs you of the life you thought you were going to have, the one you planned with your family... You can't do what you want, when you want, it's unpredictable. Life has to be adapted and constantly changed. It becomes important not to look back at what is lost and make an effort every day to look forward and think positively.'

Arthritis Care survey respondee

Arthritis key facts

- Arthritis can strike at any age. An estimated 15,000 children live with arthritis in the UK⁴.

¹ <http://www.publications.parliament.uk/pa/ld201213/ldselect/ldpublic/140/140.pdf>

² Musculoskeletal Services Framework. Department of Health (2006)

³ Health and Safety Executive (2013/4). Health and Safety Statistics. Annual Report for Great Britain. <http://www.hse.gov.uk/statistics/overall/hssh1314.pdf?ebull=stats/oct=14&cr03>

⁴ Sacks J et al. (2007). Prevalence of and annual ambulatory health care visits for pediatric arthritis and other rheumatologic conditions in the United States in 2001-2004. *Arthritis Rheum* 2007; 57(8):1439-45.

- The condition is a leading cause of pain, disability and work loss with 480,000 people living with the condition in Wales.
- There are over 200 types of arthritis, including osteoarthritis, rheumatoid arthritis, ankylosing spondylitis, Lupus and Gout.
- Arthritis conditions vary widely, but many share common symptoms such as pain, inflammation and joint stiffness. These symptoms often impact on mobility and dexterity. Many types of arthritis also cause significant fatigue.
- Arthritis can have an impact on all aspects of a person's life – from day to day activities and access to independence to family and social life to work life.
- A recent survey from Arthritis Care found that 44% of people waited over a year to seek help for arthritis.
- In a recent survey, 71% of people with osteoarthritis stated that they are in constant pain. 87% were concerned about maintaining their independence in the future due to their condition.

Arthritis – the challenges

We have highlighted below a number of the current health policy and service challenges impacting on people with arthritis in Wales.

Prevention

Arthritis is not unavoidable. Increasing physical activity and maintaining a healthy body weight can impact on a person's chances of developing a musculoskeletal condition. The numbers of people living with arthritis is set to increase, however future prevalence can be influenced by policies and behaviour now. Increasing physical exercise and keeping a healthy body weight can significantly reduce the chances of an individual developing osteoarthritis – the most common form of arthritis. For those already living with arthritis, exercise and achieving a good body weight can reduce the impact of the condition at every stage of the disease. Obese people are more than twice as likely to develop knee osteoarthritis than those of normal body weight⁵.

More than two out of three knee replacements and one in four hip replacements in middle-aged women in the UK are attributable to obesity⁶

Arthritis Care believes that public health initiatives that work to increase activity and participation in exercise and sport should be a priority for the Fifth Assembly. In addition, we believe there is scope to further highlight the link between exercise and healthy body weight and healthy bones and joints in the future. That message is needed as a primary prevention approach for the wider population to tackle future prevalence levels of arthritis and as secondary prevention for people already with arthritis to limit its impact. We need a robust public health approach to musculoskeletal health in Wales.

Orthopaedic services

We believe it is vital that current waiting times for elective orthopaedic services in Wales are reduced. We believe this should be one of the highest health priorities of the Fifth Assembly. Longer waiting times for a joint replacement can have a devastating impact on an individual, their quality of

⁵ Blagojevic M et al. (2010). Risk factors for onset of osteoarthritis of the knee in older adults: a systematic review and meta-analysis. *Osteoarthritis Cartilage* 18 (1):24-33.

⁶ Liu B et al. (2007) Relationship of height, weight and body mass index to the risk of hip and knee replacements in middle aged women. *Rheumatology (Oxford)* 46(5): 861-867

life and life circumstances. An estimated 91% of primary hip replacements and 97% of primary knee replacements are due to osteoarthritis.⁷

Rheumatology services

For people with a suspected inflammatory arthritis such as rheumatoid arthritis, early referral and assessment by rheumatology services is vital in reducing the impact of the condition long term. However, many people are experiencing waiting times that fall outside established standards. The British Society for Rheumatology's Clinical Audit of Rheumatology Services in England and Wales in 2016 found that compliance with relevant NICE Quality Standard 2⁸ – ability to see patients in rheumatology within 3 weeks of referral was at 22% in Wales⁹ (down from 28% in 2015¹⁰). Those Wales figures are lower than any region of England.

Paediatric rheumatology – services for children with arthritis

Despite its population size, Wales does not have a dedicated multidisciplinary paediatric rheumatology service. With the lack of current provision, many children are travelling to hospitals in England to access services. Arthritis can have a significant impact on many aspects of a child's life, including continuity in education and social and peer group integration. Minimising the impact of arthritis is vital for a child's development. We believe that the population size of South Wales requires the establishment of a dedicated multidisciplinary paediatric rheumatology service.

Promoting supported self-management

Arthritis Care has been at the forefront of the movement to promote supported self-management for people with chronic long term medical conditions. Self-management support enables people to better manage their health condition on a day to day basis – it can take the form of referrals to third sector services, mentoring, peer support, access to publications, helplines, training and signposting. Examples of self-management activities include taking up exercise, improving diet, losing weight, goal setting and using techniques to manage pain. People with arthritis can play a pivotal role in managing their condition and stopping it from managing them. Despite this, many people with arthritis are not aware of the difference they can make in managing their condition and many people are not referred to services such as those provided by Arthritis Care.

Many people with arthritis are coping with the daily pain of arthritis with pain killers alone when so much more can be done to limit the impact of the condition. People with arthritis should be supported to be fully involved in their health care and should be offered a personalised care plan, yet too often people go without such plans.

'24% of those with a limiting long-term illness said they had a personal care plan. 88% of those who had a personal care plan agreed that it helped them take care of their health and well-being'¹¹

⁷ National Joint Registry for England, Wales and Northern Ireland (2014), 11th Annual Report

⁸ <https://www.nice.org.uk/guidance/cg79>

⁹ http://www.rheumatology.org.uk/resources/audits/annual_report/second_annual_report.aspx

¹⁰ http://www.rheumatology.org.uk/includes/documents/cm_docs/2016/b/bsr_hqip_report.pdf

¹¹ National Survey for Wales April 2014 – March 2016. Published Feb 2016.

<http://gov.wales/docs/statistics/2015/150914-national-survey-wales-2014-15-headline-results-revised-en.pdf>

Policy Issues for the Fifth Assembly

A decade ago, Arthritis Care led a successful campaign for the Welsh Government to develop Europe's first national arthritis strategy¹². The government in England followed Wales' lead and developed its own musculoskeletal strategy. Subsequently, a national Clinical Director for Musculoskeletal Services in England was recruited to drive up standards and promote good practice. No similar role exists in NHS Wales.

Despite Wales' lead a decade ago, there is still much work required to improve health care services for people with arthritis in Wales. Since the strategy, guidelines have been developed by NICE to inform best practices in health care for people with many forms of arthritis including the most common forms, Osteoarthritis¹³ and Rheumatoid Arthritis¹⁴. Additional Standards of Care have been developed by ARMA¹⁵. Arthritis Care has been calling for the Welsh Government to develop an updated Action Plan to improve arthritis and musculoskeletal health care services in Wales informed by recent standards and guidelines and that fits with the current NHS structure and policy context. Recent Health Ministers have stated that work to align its Arthritis Directives with Prudent Healthcare will be undertaken by officials¹⁶. We are keen to see this work taken forward as soon as possible.

Arthritis Care wishes to work constructively with all stakeholders to drive forward health care standards for people with arthritis in Wales. To support the development of an updated action plan, we are currently working to establish a new Arthritis Alliance Cymru, with key stakeholders from across Wales, including representatives from key health professional groups and voluntary organisations.

About Arthritis Care Wales

We are the leading voluntary organisation working with and for people with arthritis in Wales. People with arthritis are at the heart of our work: they form our membership, are involved in all of our activities and direct what we do. We believe that people with arthritis are entitled to receive the best possible treatment and support, and to have their voice heard in decisions affecting their health and well-being.

Our central aim is to help people get their lives back, increasing their independence and improving their health and wellbeing. We do so through a range of services via helplines, including 'The Source' for young people; online forums; award winning publications; community information points; campaigning; peer support and local groups. We have most recently launched a 'Get Active for Arthritis' project in North Wales.

¹² Service Development and Commissioning Directives, Arthritis and Chronic Musculoskeletal Conditions, 2007 <http://gov.wales/docs/dhss/publications/130902arthritisen.pdf>

¹³ <https://www.nice.org.uk/guidance/qs87>

¹⁴ <https://www.nice.org.uk/guidance/qs33>

¹⁵ <http://arma.uk.net/resources/standards-of-care/>

¹⁶ WAQ70019, WAQ70021, WAQ70022, WAQ70023. WAQ70325, WAQ70325.

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