

# Sixth Group Meeting: Mental Health & Axial SpA

## All-Party Parliamentary Group on Axial Spondyloarthritis Minutes April 2020

---

### Introduction

This document contains the minutes from the sixth meeting of the All-Party Parliamentary Group (APPG) on Axial Spondyloarthritis (axial SpA). The meeting - *Axial SpA and Mental Health: Understanding the Impact & Identifying Opportunities for Improvement* - took place virtually, on 28<sup>th</sup> April, 2021.

### Formal APPG Business

#### 1. Welcome and introductions

APPG Chair Tom Randall (Conservative MP for Gedling) welcomed attendees to the sixth meeting of the APPG on Axial SpA and provided a brief overview of the meeting's agenda and objectives, which were focused on axial SpA and mental health, the current state of services and the opportunities for improving outcomes.

Dr Dale Webb, NASS Chief Executive, then gave a brief overview of the organisation's recent activities in the context of the meeting. The first of these relates to the level of support it has provided to axSpA patients in regards to Covid-19 and the negative impacts that confusion over shielding guidance and overall disruption to services have had. More broadly, Dr Webb highlighted the general impact of axial SpA on mental health and the fact that two-thirds of patients will experience some form of mental health difficulties. A sixth will have significant depression, which is both higher than the general population and for other musculoskeletal conditions. Dr Webb concluded by suggesting that this contributes to a significant overall burden of disease of mental health conditions, which are in general not being well-managed at present.

### Presentations

#### 2. Presentation from Paul Curry (NASS Trustee)

Paul Curry's presentation focused on his personal experience of living with axial SpA and the surrounding mental health impact it has had. Paul began by telling his story of the onset of his symptoms at the age 14 and the sudden impact this had on his life. He explained how the symptoms caused anxiety and embarrassment as a young teenager and operated in cycles throughout Paul's education, leading to wider mental health and emotional challenges. Paul also explained how this impacted the mental well-being of those close to him, including his parents. Several referrals, pain management clinics and appointments did not lead to a diagnosis, delaying his access to appropriate support and leading to a sense of hopelessness.

Paul explained how his situation deteriorated whilst at university, which led him to drinking heavily in social situations to try and mask the pain he was in. There was also a sense that discussion of mental health at this time was still a taboo subject. Paul described how when he did finally receive a diagnosis of axial SpA, the symptoms had worsened considerably due to the delay. Reflecting on his experience, Paul explained how thankful he is for the care he has received from his local rheumatology team in Newcastle but acknowledged that his wider mental health has never really been addressed. He also reflected on there being no apparent pathway to access appropriate mental health support.

Paul also touched on the relationship between the condition and employment and expressed concern for the many people living with axial SpA who feel unable to go to work. Paul described how he has been relatively fortunate to be able to work for a family company who are understanding about the flexibility he sometimes needs to manage his axial SpA, but for many this is not really available. Paul concluded by setting out the immense value and benefits that would be realised in axial SpA if patients were able to access mental health support when they needed it.

#### 3. Presentation from Dr Sophia Steer (Physiotherapist & Researcher, King's College NHS Foundation Trust)

Dr Sophia Steer's presentation provided an overview into new research on the emotional impact of living with axial SpA. This was split into a summary of the early findings from the first phase, and then an overview of the purpose of the second phase of the study which is due to start shortly.

Dr Steer began by setting out the context for the study. Many people living with axial SpA experience psychological distress and 40% of patients report some depressive symptoms. Pain, fatigue and disability often contribute to feelings of helplessness, social isolation and anxiety. These feelings are most prevalent in the year after diagnosis. Dr Steer described how patients with axial SpA commonly report the emotional elements of the condition, yet these symptoms are frequently overlooked during consultation processes. She also confirmed that there is a strong relationship between higher levels of mental well-being and positive prognosis.

Dr Steer went on to describe the aims of the project which were to deepen our understanding of the psychological impact of living with axial SpA and to identify the facilitators and barriers to positive emotional well-being. Phase 1 of the project involved a systematic qualitative review of literature relating to axial SpA, with 13 studies synthesised for further analysis. The studies were published between 2001-2019 and included 435 participants, 25% of which were women. Whilst none of these studies were primarily focused on emotions but there was a dominant narrative that emerged around the adverse impact of axial SpA on emotional well-being. Key barriers to positive well-being included a lack of authentication, stigmatisation associated with back pain, and delayed diagnosis. This led to anger, frustration, disappointment and sadness in many instances.

Positive facilitators for emotional well-being included a definitive diagnosis, exercise, anti-TNF medication, work, good knowledge and self-management of the disease, as well as support from family and friends. This often led to feelings of hope, happiness and satisfaction.

A social media review was also carried out and identified 500 relevant items for analysis. Posts were categorised under the following four themes: daily challenges, self-concept, and professional and personal relationships. Pain was a barrier to emotional well-being across all four themes and key concerns related to the difficulty of carrying out daily activities whilst dealing with symptoms. Overcoming challenges with the disease led to pride and positive emotions, while changes in physical appearance led to more negative self-evaluation. A lack of understanding and acknowledgement by professional employees contributed to vulnerability whilst personal relationships were impacted by issues such as being unable to carry out duties as a parent.

Dr Steer went to describe the next phase of the study which will include diary interviews and convening focus groups. This would seek to provide more evidence about emotional well-being during the early stages of disease and immediately following diagnosis, addressing the gaps from the literature and social media review. To conclude Dr Steer set out how the review has highlighted the negative emotional impact of axial SpA across the life course, with significant consistency in terms of the barriers to emotional well-being.

#### **4. Presentation from Dr Ben Thompson (Consultant Rheumatologist, Newcastle Hospitals NHS Foundation Trust)**

Dr Ben Thompson's presentation focused on current service delivery in the context of mental health and axial SpA and opportunities for improvement. This began from the perspective of Newcastle's axial SpA service which covers a large geographical area. The team is made of 4 rheumatology consultants, a specialist nurse, an extended scope physiotherapist and a rheumatology occupational therapist. It also part of the NASS 'Aspiring to Excellence' programme.

Dr Thompson acknowledged that mental health problems are common amongst his axial SpA patients, with strong prevalence of significant depression. This can be devastating for some individuals, particularly as anxiety and depression often have an impact on patient reporting of their condition. Mental health is included as part of routine outcomes measures, including the ASQOL questionnaire and the MSK-HQ, which ensures that this information is available to healthcare professionals. This can provide a platform for appropriate intervention, however there is limited inclusion of mental health as part of national guidelines for axial SpA.

Mental health issues are often presented to rheumatology professionals as patients generally have a better relationship with their consultant as opposed to primary care. However, these professionals will have had very little training in mental health support and the referral pathways are subject to variability and delays. Dr Thompson also described how mental health is often viewed as being separate from rheumatology, which has caused issues when it comes to securing additional funding.

Dr Thompson then provided an overview of the services available in Newcastle for these issues. This includes access to a Rheumatology Occupational Therapist, who provides education for patients struggling to cope with the disease, and clinical health psychology. Coverage of clinical health psychology across UK rheumatology teams is at 40% and these teams can deal with more complex cases on a 1-1 basis. More longer-term issues will require referral back to the GP, whilst patients can also be signposted to self-referral resources such as the talking therapy service in Newcastle. For the most serious issues, a crisis team is available with psychiatric help 24 hours a day.

Dr Thompson's presentation concluded with an overview of what best practice might look like. He suggested that this would likely involve effective better identification, awareness of local services to enable appropriate referral, dialogue between different providers to develop referral pathways and ensuring that best practice is shared. Mental health support and treatment could be included in national guidelines, whilst nurses and specialists could also receive more comprehensive training in this area.

### **5. Presentation from Dr Max Henderson (Associate Professor of Psychiatry, Leeds Institute of Health Sciences)**

Dr Henderson provided his perspective as a mental health professional and focused on how the management of long-term conditions could be improved. This began with an overview of his current role as a liaison psychiatrist providing assessments, diagnosis and management plans for patients experiencing both physical and mental health issues. These liaison psychiatrists are often trained in psychiatry and hospital medicine.

Dr Henderson then went on to define multimorbidity, which involves patients with two or more long-term conditions and is not restricted to the elderly. These long-term conditions cannot be cured but require careful management. He described how multimorbidity is neither rare nor special, however it is unfamiliar due to the way medicine is taught. Students receive little guidance on the management of one condition in the presence of another and whilst this is clinically challenging, Dr Thompson described how the work of his team has demonstrated that it can be done. Multimorbidity was also referenced as an area which is greatly affected by social circumstances and the incidence is much higher amongst disadvantaged groups.

Conditions that occur together often influence one another and this is the case with musculoskeletal and mental health disorders. This leads to issues such as pain, trouble with sleeping, motivation as well more malign complications associated with social isolation and employment difficulties. The impact on employment is stark, particularly when patients are depressed as they have much reduced capacity to deal with the pain associated with their condition. The employment rate of individuals experiencing both MSK and mental disorders is half that of patients who suffer from MSK alone. Common mental disorders are often the tipping point which leads to a potential exit from the labour market and wider social isolation.

Dr Henderson then assessed the current state of mental health services which are not well equipped to deal with this scenario. They are underfunded, particularly in research terms, and the ambition of parity between physical and mental health is still a long way off. Services are also subject to significant variation in accessibility and are overwhelmed, particularly in the community sphere. This has only worsened during the pandemic. They are also poorly aligned to the needs of patients with multi-morbidities due to the focus on risk as opposed to clinical need.

Key measures to address this include education and training, improved collaboration and communication. Dr Henderson then described how these ambitions have been mentioned frequently in the past and much more action is required. This will involve defining a new purpose of medicine and moving beyond symptom alleviation to optimisation. For many people, this optimisation could involve returning to work or fully interacting with family and friends. This will create a shared endeavour between colleagues due to the necessity of greater collaboration. Dr Henderson concluded by suggesting that the management of musculoskeletal and common mental disorders could develop into a template for multimorbidity through adopting this approach.

### **6. Presentation from Sue Brown (CEO, The Arthritis and Musculoskeletal Alliance)**

The final presentation was delivered by Sue Brown, who shared the perspective of ARMA on the future of MSK and mental health care. Sue described how mental health has been a priority for the organisation in

recent years and in 2019 this involved hosting a roundtable bringing together both mental health and MSK stakeholders.

The roundtable identified several key insights on factors that impact mental health for patients with MSK. This included long delays in diagnosis, feelings of isolation, and the problems associated with transitions. These transitions include the whole diagnostic process, changing medications and impacts on employment. These insights provided the basis for four subsequent recommendations, two for services and two for individual professionals. For services, the 'increasing access to psychological therapies' programme should be expanded to cover long-term conditions, and more competencies need to be developed around MSK pain. Mental health support needs to be more integrated, with health psychologists working as part of the rheumatology teams.

For professionals, the roundtable advised that patients should be asked about their mental health. Sue described how professionals can be reluctant to do this due to fear of escalation and limited confidence in the referral process. With the presence of a health psychologist in the team, professionals immediately become much more confident in their ability to talk about mental health. The second recommendation for professionals was to provide sufficient signposting to patient organisations such as NASS. These organisations have a massive role to play in providing a forum for peer discussions and directing patients to appropriate support.

## 7. Question and Answer Session

Tom Randall MP thanked the speakers for their presentations and opened the floor for wider group discussion, which was chaired by Dr Dale Webb. A summary of this discussion has been included below:

## 8. Discussion Overview

Several axial SpA patients were invited to the panel to share their experiences of living with axial SpA. Key reflections provided by patients related to:

- **Employment:** There is a significant amount of work that needs to be done to support patients in employment. It was also acknowledged that the provision of mental health support within employment is rare and most people do not feel as though they can afford to take any time off. Even when patients are provided with time off work, the time limit associated with this can cause problems and put pressure on the recovery process.
- **Managing pain:** The experience of pain from axial SpA often has knock-on effects and can lead to other issues such as excess alcohol consumption or over-using medication as a nullifying strategy. It was also acknowledged that the impact of the pandemic has exacerbated the experience of pain in many instances.
- **Current service provision:** Contributors welcomed the focus on mental health during the meeting and the recognition of its close relationship to axial SpA. This was contrasted with their personal experiences with healthcare professionals throughout their axial SpA journey, who have generally not asked about mental health. There is also no clear referral pathway once these issues have been raised.
- **Best practice:** It was suggested that a key area of best practice would involve incorporating a clinical psychologist within the rheumatology team. This would provide the necessary reassurance for both patients and professionals to discuss mental health issues. It is also important to make the distinction between what is ideal and what is feasible. Ideal service provision would likely involve management by multidisciplinary teams containing a specialist with expertise on the effects of long-term pain on mental health. It was acknowledged that this would require both significant investment and patience to embed. Finally, it was suggested that the issue needs to be widely raised during conversations between clinicians and patients as part of an overall measurement process to quantify the scale of the problem.

Several rheumatology professionals were then invited to the stage to discuss their conception of best practice and how this could be developed. Key reflections provided by the clinicians included:

- **Patient voice:** Best practice design should be guided by the recommendations of patients which will rely on clinicians listening to their perspectives and experiences.
- **Resources:** It was acknowledged that most rheumatology departments will find it difficult to provide appropriate resources to fund specialist mental health expertise. Mental health support for axial SpA patients is clearly an unmet need, and an example audit was referenced which found that a third of patients with axial SpA scored very highly on a hospital anxiety and depression scale. Self-management techniques for patients have been developed but it was acknowledged that these individuals ultimately require 1-1 support. The provision of mental health support was also referenced as being linked to improvements in outcomes.
- **Building the business case:** A key opportunity was identified around building a business case for improved mental health support in axial SpA. Many patients suffering from chronic conditions are likely to experience mental health issues, however it was felt that physical health still constitutes the main dialogue due its greater visibility. Building the business case for mental health funding has involved collecting extensive data on patient populations, however the goalposts for securing funding often change. Past work has demonstrated that patients can benefit enormously from just a short intervention and arguments were much more powerful when they mentioned the financial benefit of this. These business cases need to be more widely produced and disseminated to advocate for the funding of a full-time clinical psychologist and a councillor.

## 9. Meeting Close

Dr Dale Webb moved to bring the discussion to a close by providing an opportunity for the APPG co-chairs to offer any final remarks, whilst also referencing the possibility of hosting follow-up meetings to discuss these issues in further detail. Lord Campbell-Savours raised the issue of employment and to what extent mental health issues affect this. He spoke from his personal experience where an alternative career to politics would have severely affected his ability to go to work. Tom Randall MP then provided his reflections on the very raw nature of the discussions which have gone to the heart of the experience of axial SpA patients in recent years. The issue would be taken forward as a key area of focus in the APPG's activities, as well as with NASS and other stakeholders. He then concluded by extending his gratitude to participants for their presentations, as well as to attendees for giving up their time.

## Further Information

For any further information about this meeting or the APPG on Axial SpA, please contact [appgsa@mandfhealth.com](mailto:appgsa@mandfhealth.com)