Debbie Cook

Chief Executive

National Ankylosing Spondylitis Society

NASS & AS

- NASS is the only UK registered charity dedicated to ankylosing spondylitis (axial spondyloarthritis) (AS)
- Membership Charity
- Small charity – 6 members of staff
- AS is an inflammatory arthritis of the spine
- AS affects around 200,000 in the UK and starts in late teens

How NICE guidance looked

TA143 (2008) and TA233 (2011)

- Anti TNF could only be considered when there was evidence of x-ray changes (advanced AS)
- 3 out of possible 5 drugs available
- Patients could only try one anti TNF and could not switch if it was not effective or efficacy worse off over time

How NICE guidance has changed

TA383 (February 2016)

- Anti TNF can be considered when there is evidence of inflammation on MRI OR x-ray changes (early AS)
- All the drugs options recommended
- Treatment with another anti TNF recommended for people who cannot tolerate or whose disease has not responded or has stopped responding

How NASS made a difference

Representing the patient view

- NASS short survey
- Emailed to 3800 plus on NASS website (only one entry per IP address)
- Only for people with Axial Spondyloarthritis or Ankylosing Spondylitis living in England
- Introduction as to why so important
- Not just for people on anti TNF
- Replies anonymous
- 608 responses

How NASS made a difference

- Used survey results to write our submission to NICE
- Attended first Appraisal Committee as patient representatives
- ACD recommended use of anti TNF in early AS and 4 out of 5 anti TNFs BUT did not recommend one of the drugs OR make a recommendation regarding switching
- SO.....carried out a second survey
- This time 800+ took part over 2 weeks

How NASS made a difference

- 92% of people with AS said they were dissatisfied with the failure to recommend switching
- Those who had switched were asked about the benefit and 79% felt switching had a moderate to large benefit
- 77% were dissatisfied with decision not to recommend infliximab for AS
- Submitted survey findings to NICE and attended second Appraisal Committee Meeting

Key Learning Points

- Important for a patient organisation to show that it is representing the views of patients
- Data from patient surveys is influential
- Even small patient organisations can carry out large, scale influential surveys at a low cost

NATIONAL ANKYLOSING SPONDYLITIS SOCIETY NASS UK

Working in partnership with the University of Lancaster, patients and health care professionals to develop the NASS Research priorities

Methodology

1. Call for research priority suggestions from NASS members: over 150 responses
2. Workshop held at Lancaster University in February 2013
   - Attended by 25 people, including Debbie Cook (NASS CEO), Dr Stephen Simpson (Director of Research, Programmes and Information at ARUK), Dr Lynne Goodacre and Dr Elham Kashefi (Lancaster Medical School)
   - NASS member suggestions reviewed, elaborated on and added to
3. Findings from workshop formulated into survey...

Questionnaire

- 39 research priorities generated from workshop
- Divided into 5 categories
  - Managing your AS
  - Psychological Health and Wellbeing
  - Lifestyle
  - Medical/clinical Management of AS
  - Exercise, activity and sport

Top 5 research priorities

1. Develop a greater understanding of AS triggers that lead to flares **(4.56)**
2. Evaluate different ways of improving GP/HCP understanding of AS **(4.53)**
3. Develop better understanding of the impact of fatigue on people with AS **(4.37)**
4. Provide better understanding of the type of exercise needed depending on age/severity **(4.37)**
5. Develop a self-management programme to help people manage their AS effectively **(4.34)**

Other research priorities

6. Review anti TNF to help people make more informed decisions **(4.31)**
7. Review efficacy and side effects of medications to help people become more informed **(4.30)**
8. Develop a greater understanding of the impact of dealing with other conditions associated with AS **(4.29)**
9. Evaluate different strategies to manage pain **(4.27)**
10. Develop and evaluate different approaches to exercise AND improve information flow between primary and secondary care **(4.20)**

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