

Appendix I: Expert witness testimonial

I.1 Physical aids for spondyloarthritis

Review question 18

- What is the effectiveness of physical aids (for example, braces) compared with standard care for managing spondyloarthritis?

I.1.1 Expert advice provided by; Clare Clark (Expert Witness), Advanced Practitioner Occupational Therapy, Powys Teaching Health Board

Any interventions missing that should be included.

I wondered if it would be helpful if I identified my treatment approach with this cohort of patients. The elements of most of these are touched on in the document.

Following on from a referral into my service, a patient is seen on a one to one basis and a collaborative agenda is set. This ensures that the patient's needs and concerns are highlighted at the start.

My focus is on empowering a patient to self manage their condition. The first step is a discussion to ensure they have a good understanding of their condition to enable them to make informed choices as to their intervention throughout the Health Service.

The main issues which these patients tend to present with are: pain, fatigue, poor sleep, stiffness and the psycho-social impact of their condition. I offer a goal focused self management programme either individually or in a group. This covers; pain management, pacing and planning activities, relaxation (as a tool to managing pain and facilitation a restorative sleep pattern) SMART goal setting (is carried out thereby teaching patients effective problem solving which can be transferred to all areas of their lives).

The self management groups are multidisciplinary and the physio role is around educating on exercising with pain, setting a baseline for exercise and building a graded exercise programme.

Intervention includes discussion around communication and how to communicate with, family, friends, health professionals, employers and colleagues.

The patient creates their own 'toolkit' to manage their condition and manage flare-ups.

Issues around work often arise and I use the Fitness for work documentation. This involves a discussion where the patient identifies what the issues are with regard to work and comes up with possible solutions. This empowers the patient to have a productive discussion with their employer with the aim of collaborating in order to maximise occupational performance.

Back braces

I do not know of any situations where a back brace would be recommended for this cohort of patients. A graded exercise programme to maximise muscle strength and stamina and regular movement would be the preferred line of treatment.

Physical aids such as wrist braces

Over the last 15 years, I have seen a vast improvement in medications which has reduced the number of wrist braces/splints that I provide as a treatment option. Splinting is very much on an individual basis and splints would be issued to provide support during function tasks, (occasionally over night to maintain a functional position of the hand) and reduce pain. When a splint is provided, an exercise programme is also issued. Lycra compression gloves can be of benefit to reduce swelling and pain, thereby optimising hand function.

I.1.2 Expert advice provided by; Nicky Bassett-Burr (Co-opted GDG member), Occupational Therapy Hand Specialist, Western Sussex NHS trust

Looking at the protocol, are there any interventions you think are missing and should be included?

Kinesiology Taping – A relatively new method of modality in the UK but one which clinicians are seeing very effective outcomes in treating oedema, inflammation, pain and assisting function without over restricting movement, thereby maintaining strength.

Is there anything from your experience, that you think should not be used as a physical aid – for example would back braces restrict movement and exacerbate the condition?

Each and every client needs to be assessed on an individual basis with regards to possible contra – indications versus benefits for physical aids.

Potential Benefits: Physical aids can help reduce pain & inflammation, increase, stability, function, conserve energy, improve confidence and assist with Joint Protection Techniques

Potential Contra-Indications; Over dependence can reduce range of movement & strength, cause physical damage, for example a hand splint rubbing over a bony prominence). For some clients physical aids are aesthetically unacceptable as they feel that they imply disability. Some splints / braces may limit functional ability by restricting range of movement and cause irritation or discomfort.

From your experience, how effective have you found physical aids in managing spondyloarthritis and which are the most effective?

In my experience splinting / braces for the hand are most effective for;

1. Heavy activities of daily living – where either lifting or repetitive activity is involved.
2. Helping to reduce or limit pain and inflammation from by providing support and limiting range of movement.

Generally in my experience, prefabricated (off the shelf) neoprene and or Lycra wrist splints or thumb “spica” splints are sufficient provided they fit effectively. Otherwise a custom neoprene splint is indicated, which may contain thermoplastic inserts if necessary.

Occasionally a more supportive and restrictive custom made thermoplastic wrist splint or thumb spica may be indicated for more severe and painful conditions.

Minor adaption's such as jar / bottle openers, key turners, wide handled vegetable peelers; adaptive pen, elasticised shoelaces, grips are often helpful to clients.

I know your specialism is hand occupational therapy, but could you advise us more broadly about aids for axial spondyloarthritis?

This really is not my area of speciality, so I can only offer a limited opinion. The recommendation of appropriate aids will be individually based dependant on the severity of the client's disease, their physical disability, as well as cognitive ability, their environment, support and occupational demands. However listed below are general adaption's which could be considered;

For Personal activities of daily living – grab rails, perching stool, shower stools, tap turners, walk in showers, bath seats / bath master.

Domestic activities of daily living – kitchen trolley, perching stool jar /bottle openers, key turners, wide handled vegetable peelers and adaptive cutlery.

Plus optimum height for chairs & beds – adapted with raisers if necessary, stairs / steps may benefit from banisters / rails.

Ultimately the environment may need to be adapted for wheel chair access.

5) Anything else you think important in answering this question.

- Joint Protection and Energy Conservation Techniques.

Adopting Joint Protection Techniques can help manage pain and Activities of Daily Living (ADL) more easily. Theoretically, adopting Joint Protection Techniques, may help limit further deformity / damage to joints.

- Energy Conservation

can be utilised to adapt day-to-day activity to help improve quality of life, by conserving energy for those activities that are deemed most important to the client.

- Gentle Range of Movement and Strengthening Exercises.

The SARAH Trial (Strengthening and Stretching for Rheumatoid Arthritis of the Hand) a RCT conducted by Warwick University 2012, found that an extra exercise (on top of standard care) improved function and quality of life, with out increasing pain or deformity.