

A Turn for the Better.

By Juliette O’Hea

Having the chronic disease axial spondylarthropathy (AS), has had its advantages. It has given me the opportunity to be part of a complex, evolving and fascinating world. Before my symptoms really kicked off whilst working in New Zealand, I was destined to follow a long career in general outpatient physiotherapy. Now looking back, however, I had rather fallen into rather than chosen this path.

In 1992, following my spell recuperating from reactive arthritis (see previous blog for more information) and under the expert care of Dr Ian Gaywood at Swindon Hospital, my journey began. My role as metrologist soon expanded into clinic work encompassing all aspects of patient care and assessment.

At a time when outcome measures were not yet standardised, I then joined Dr Calin and his team at ‘The Min’ in Bath interviewing patients in preparation for the Bath indices. These were exciting times.



Subsequently, I heard about the inspirational work of physiotherapist, Sue Fletcher, and her team of Allied Health Professionals (who were mainly Physiotherapists) at Christchurch Hospital. As part of her dedicated rheumatology follow-up clinic, I continued to be mentored as I learnt to decipher blood results and X-rays, and advise patients on their (rather limited at that time) medication. We were shown how to inject shoulders, wrists and knees. We were ahead of our time but few people knew of our existence.

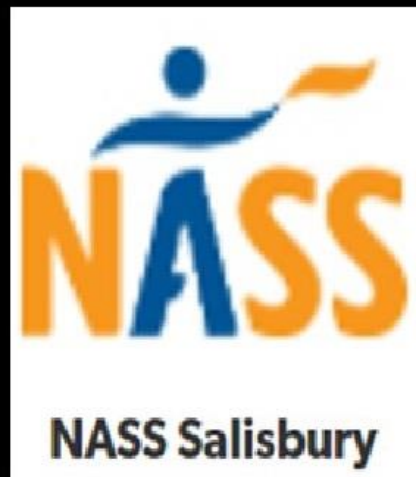
In 1994, acknowledging the need for more formal training, the whole team were encouraged to undertake a specially devised Post Graduate Diploma and Masters course in Advanced Clinical Rheumatology at Bournemouth University. This comprehensive 2 year course was compiled by Sue Fletcher and Dr Karen Mounce, Consultant Rheumatologist at Christchurch Hospital.

Once graduated and buoyed up with enthusiasm, we decided to call ourselves Rheumatology Practitioners. We thought that as an army of practitioners we were going to conquer the world!! Sadly this was not to be the case. After we had graduated, the University course was never repeated and that is a great loss. The course relied on undergraduates being part-funded by their hospital but at the time, few hospitals shared our enthusiasm or had the funding.

However, armed with the skills and confidence, I decided to start up more rheumatology follow-up clinics closer to home. Despite being a Physiotherapist and not a Nurse (who traditionally took these roles), I managed to convince the medical staff at both Salisbury and Southampton hospitals that they needed me as a side kick to lessen their load and that I was also good value for money! The Consultants were extremely trusting and supportive in my work with the patients and they had an open door policy in times of need. Patients were happy to be seen by someone who could empathise with their symptoms, was at the end of the phone in times of need and could offer them the time they needed in clinic. We were still pre-biologic therapy at this point so care needs were complex and drug side-effects were a constant issue.

Salisbury and Southampton had an excellent Physiotherapy and Occupational Therapy department and all my patients spent time in these departments as part of their programme. Although I was not

working as a traditional Physiotherapist, my previous experience in MSK came in useful and with the support of NASS, I over saw the creation of the Southampton and Salisbury NASS exercise groups.



Then, the late, great, Physiotherapist, Jane Barefoot nominated me as Physiotherapy Advisor to NASS; but walking in her footsteps proved to be a difficult task. I felt I could not carry the burden alone and that patients so desperately needed more help. A group of rheumatology physiotherapists heard my cry for help and AStretch was born in 2001. The not-for-profit organisation has subsequently grown into to what it is today making a huge impact in patient care and knowledge dissemination.

Meanwhile I continued my work as Rheumatology Practitioner and I really felt that I had found my calling. For nearly a decade, I enjoyed helping to solve complex issues, gaining knowledge and making good friendships with the patients and staff. When I left work in 2004 to look after my young daughter, biologics were in their infancy and life for the staff and patients were about to change radically. Sadly it took many more years before AS patients could benefit from Biologic therapy but I can talk from experience, it has been a life saver.

Nowadays there is so much more help, support and guidance for patients with AS. NASS now employs 10 staff and amongst many other

initiatives, is involved with parliamentary campaigns to increase the profile of AS and AStretch is an integral part of the organisation.

In hospital departments across the land, rheumatology is taking centre stage and there are Allied Health Professionals working as clinical specialists making a big difference. Many of the frontline staff are members of AStretch and many have contributed by attending AStretch courses and conferences. As a member of AStretch, I feel privileged to be working alongside physiotherapy colleagues so passionate about the care and wellbeing of AS patients and their families. It has been so rewarding and such a pleasure to be part of this world and I consider myself lucky as my career would never have gone in this direction without my AS.



Juliette