

Supporting the supporters

By Claire Jeffries



Working within the field of AxSpA over the past 20 years has given me the opportunity to look at many different amazing projects to try and enhance the care and services that patients have locally in my area. From service redesign to patient education sessions, hydrotherapy exercises groups to community engagement programmes. All of these interactions are continually aimed at supporting patients to self-manage their condition long term. The fact that patients spend only 3 hours a year with health care professionals and then have to “self-mange” for the remaining 8757 hours of the year is a great reminder of how our input can be invaluable to help support patients to live a happy life with their condition. But what about the other people in the patients’ life ? The ones who spend the majority of the 8757 hours with them. The people who may, or may not (!), help support our patients – their family and friends. What input and role do they play?

Within our roles we have the scope and “permission” to spend time working with our patients, trying to educate and support them in self-management but do we spend enough time educating their family and friends to help them support our patients during all those hours when they are not with us? Are we allowed to spend time specifically educating & supporting the patients’ friends and family? Do “we “ [healthcare managers] acknowledge that time educating and seeing the family and friends maybe an essential part of the patients’ overall care and support strategy? What we are really asking then is.....”Do we invest enough time supporting the supporters?” So to give food for thought I want to share a few experiences of how my work includes different ways of supporting the supporters.....

Starting at the basics, when I reflect back and look at when I first started work within this field most of the patients attended their treatment and clinic reviews on their own. I will happily admit that back in those times I loosely asked what support a patient had at home from their family and friends but it certainly was not always the focus of our discussions. Fast forward to the last 5 years and there is a whole new world! My personal recognition that friends and family are key in supporting patients to self manage in all elements of their disease is now paramount to my communication and support that I give to patients. To that end in my local area we actively encourage all patients to bring a family member to every consultation that they have with us. Through our appointment letters, patient clinic information and in person, the offer is always there. Within the clinic some family members just sit, listen and learn about the condition and its management. This can be invaluable for them to then offer moral support and encourage self management to the patient through their greater understanding of the condition. As an example the wife of a patient in clinic become very emotional when we discussed the fatigue element of the condition and she commented: "I never realised this could be part of his disease...I thought he had just stopped wanting to go out as he was so grumpy, tired all the time and using work as an excuse...".

Some family members become very involved in the clinic discussions and offer invaluable opinion on how they see the patient is really doing at home and in life. Perhaps giving us a true insight when the patient simply tells us they are "doing ok". Along side this the discussions can often mean the patients' themselves have "light bulb" moments when something is raised that they had not recognised or acknowledged as affecting them and their condition. In a recent clinic for example one of my patients attended an urgent appointment on his own describing what seemed to be an acute flare of symptoms even though he had been stable on a biologic treatment for the previous year. He could not identify any changes that may have caused the acute flare and raised concerns that his biologic was no longer working. Inflammatory markers were normal and full dose of drug had been taken. There were no other medical concerns to potentially warrant the change. On a 3 week follow up review he attended again and having seen his pain increase and coping ability decrease his wife came with him as she was concerned. Bloods were still normal (not unusual for some AxSpA patients), so we looked at alternative possible causes for the increased pain and fatigue. Although he had not felt it significant at the time, his wife did mention the recent death of his father.....a sudden event that she stated "had knocked him [our patient] for six" at the time. That he had not been sleeping well since the death as she was aware that he was constantly restless at night. That he had increased his working hours to "stay busy" and not focus on the death of his father. Through conversation after on how stress, work, and lack of sleep can affect his condition there seemed to be a real lightbulb moment for our patient on how this event could have been the cause of his apparent increase symptoms. This insight from his wife certainly positively influenced the patients treatment choices moving forward...his discussion moved from wanting to switch biologic to looking at counselling for his bereavement, sleep hygiene strategies and pacing of his work hours!

Some family members then go one step further and ask what else they can actively do to help support their loved ones. From agreeing in discussion what exercise classes or activity they may do together moving forward every week, to agreeing a strategy at home on how the patient can advise they are having a bad day without making a fuss and the family chores or activities for the day being modified accordingly. This latter

point worked well for a family where the mum [our patient] would simply blue tack a picture of a happy face or a slightly sad face to the fridge door to indicate that it was a good or not so good day. Her husband would then offer to cook dinner for example or come up with alternative activity ideas for the kids for the day, being mindful that his wife may not be able to do as much as normal but would still want to be involved.

As a final note, any family involvement within an appointment has to be at the explicit consent of the patient of course. If they are happy though and the family are happy, any level of involvement from a family member in a clinical appointment I feel can be invaluable in the patients overall self management.

Along with my work at a local level with family and friends I have had the great honour of working with NASS on delivering the friends and family sessions at several of their members days. The last was a recent as June this year. All of the days prove to be diverse, humbling and emotional sessions. The format of the sessions each year changes: mini presentations on elements of the disease, open floor questions and answers and this year the AS game of life. This last session saw family and friends move round a game board answering and discussing elements throughout life that may or may not affect their game board character (who just happened to have AS!).

Discussing the use of turmeric, what you would do if you won £5,000 on a prize draw or what you would do if you were approached to be part of a new drug clinical trial – all sorts of medical, social, positive and negative elements of life were discussed as the game progressed and allowed us as facilitators to have open discussions with those there. Inevitably, as was the intention of the game, the statements on the game cards led to other topics as the family and friends opened up more, asking questions that were important to them. We even discussed if different high tension TV shows could influence how a patient with AS may feel through somebody feeling emotional or tense when watching TV!

Being a member of NASS can prove invaluable to our patients but also to the family and friends as they have access to these member days and the specific sessions that are hosted for them. Acknowledging that not all will be able to attend the days though, at my unit we try to recreate the family and friends session each year for our local district. A small donation of money for refreshments from our charitable funds, invitations to all via our NASS group and clinic patients are organised. Scheduled as an early evening session of 2 hours we normally coincide it with our NASS group evening as a sneaky bit of branch promotion for these who may not be members! Supported by the wonderful team I work with we try to get the lead NASS physio, a nurse and consultant along to our session but any combination of staff can make a successful event.

I guarantee that some of the NASS group and their family and friends will insist that after living with the condition for years they do not need to attend any sessions as what could they possibly learn?. I would beg to differ though especially considering the rapidly changing world of medicines management and our increased knowledge about associated conditions and their management. I recall clearly during one of our events the shocked wife of one of our NASS members who had been with the group for 19 years. We were discussing the recommendation for patients to exercise daily for their AS – “you mean he should be doing more than just coming to NASS once a week? He could / should have been exercising daily?...he could be using our gym at home for example??”. I think after the session the member had no choice but to increase his exercise regime with the support of his wife!!!



On a much larger scale locally we also host full multi condition, off site education days for patients and their family and friends. Although planning and financial support is key for such an event the benefit is unquestionable. For most of the days (inflammatory arthritis, connective tissue, osteoporosis day) we see anywhere between 300 -400 people attending. We take advantage of the inflammatory arthritis day to offer specific breakout sessions for AxSpA. In these sessions we encourage patients and family together. We find these sessions are really effective for those who do not work or are retired but also those who feel they benefit from taking annual leave to have a day of education about their condition, medicines management, diet, podiatry and everything else in between. We often have one to one slots with the team as well during the day that people sign up for – with one patient this was undertaken in the relaxed atmosphere of a refreshment area with comfortable sofa chairs, coffee and cake – quite different to the sterile clinic room setup and proved just the alternative atmosphere that both our patient and his wife needed to really communicate with us. Indeed this one session with us saw a complete shift in discussion for the patient and his wife – for the first time he openly talked to her about his stress at work, his want to reduce some of his hours but the self inflicted pressure that he felt to continue as the bread winner for the family. His sadness that he could not play with his young girls easily due to his pain and fatigue and for the first time his confession to his wife that he felt “down” in mood most days but had been trying to shield her and his girls from his true emotions. Pleasingly as a result of our gathering at the event this couple now come to clinic appointments together, both realising the value and commenting that the appointments provide great support to both of them. Work modifications, open communication and an overall happy life together has been the most satisfying result for them.

So, the value of supporting the supporters I think is unquestionable for all of our AxSpA

patients. We all become invested in the care and overall well being of our patients and a significant part of that can be our interaction and support with their family and friends. My 3 top tips to get you thinking:

- 1) Start with the basics – encourage your patients to bring a family member to their appointments – this may even be as simple as a leaflet drop to all of your patients, encouraging their attendance.
- 2) Consider hosting a family and friends event – no patients, no secrets, no question is too silly! You may plan some specific education points that you want to get across to them such as the aetiology of the condition or the developments in medication. You may just want to open the floor to their questions.
- 3) Get in contact – NASS and AStretch have a wealth of experience in supporting the family and friends of AxSpA patients – we are all happy to share our experiences or give you any support we can to set up programmes or events in your area



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