

Editorial

The role of patient organisation in fibromyalgia and related syndromes

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There was a time, not so long ago, when patient organisations simply were not there. Physicians had their organisations – the American Medical Association has been around ever since 1847 –, they wrote articles in journals, attended conferences and debated the tricks of their trade, but patients were on their own. In all interactions between patient and physician, it went without saying that the doctor knew best anyway, that he was there to treat and hopefully save the patient, and that was that.

Then, things started to change. First of all, as a cultural shift, medical paternalism saw its demise. Concepts such as patient autonomy were galvanised and became ever more acceptable, while new paradigms, such as shared decision making, sprouted into existence. No less important, the rise of the mass media, the internet and eventually social media, made it ever-so-much easier for patients and their families to communicate with one another, to exchange ideas and experiences and to share information. Noble prize laureate Bob Dylan really nailed it with his succinct title “the times they are a’changin”.

As all this took place, the idea of patients organising and working with one another became truly inevitable. Patient organisations became a reality in more and more fields of medicine.

Historically, patient organisations have taken a particularly important role in combating rare and orphan diseases. In conditions such as Lymphangiomatosis (LAM) (1) and Huntington’s disease, in which the mere possibility of reaching sufficient numbers of patients in order to orchestrate a clinical study was hitherto impractical, patients got together through the internet and eventually collaborated with researchers in order to achieve clinical trials which provided some hope for effective treatment (2).

In such rare conditions the role of patient organisations now seems almost self-evident.

Nonetheless, the role of patient organisations spans beyond combating rare, “orphan” diseases. In fact, the term “orphan disease” may need some clarification and disambiguation in this context. Commonly used to describe rare diseases, *e.g.* a disease with less than 200,000 cases in the USA, the term has also been applied to conditions which appear to be neglected by the medical community. Intriguingly, it is precisely this class of disorders which share with the truly rare conditions an added value for the activity of patient organisations. Fibromyalgia is in many ways a paradigmatic example of a condition which is on the one hand anything-but-rare, and on the other hand highly neglected (and thus “worthy” of the orphan designation). While affecting as many as 2.5% of the entire population, fibromyalgia is a condition which continues to be labelled “controversial” and patients diagnosed with this condition continue to encounter stigmatisation and disbelief, as they struggle to cope with their chronic and debilitating condition. For reasons which appear to be connected more to medical sociology than anything else, derogatory terms such as “heart-sink patients” (3) or just “psychosomatic” continue to be used by doctors, derailing the rapport between fibromyalgia patients and their doctors and increasing their sense of isolation and frustration.

It is on this background that the role of patient organisations becomes so important in the field of fibromyalgia. The fact that symptoms are so diverse and difficult to diagnose, has led many doctors to be less than sympathetic towards these patients and to regard them as either not really sick or sim-

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ply lazy. This creates frustration among patients and this is exactly the place where patients' organisation steps in. Over the last 18 years the Israeli fibromyalgia and chronic fatigue association (ASAF), has acted in Israel to bring patients together and speak for them.

The organisation sees itself as the bridge between patients and physicians, promoting the dissemination of updated treatment, information and inviting patients to take part in clinical trials. By lobbying and promoting research, even in controversial directions, such as the highly heated debate surrounding the use of medical cannabis for fibromyalgia, it enhances awareness, making both doctors and the officialdom more receptive to new ideas and concepts. On the other hand it helps patients filter unreliable information and "treatments" and false promises for healing.

The activities include support groups that give patients and families the feeling that they are not alone, that there are others that cope with fibromyalgia just like them and that "someone understands and supports". It invests in education, through annual conventions, where reputable leading physicians and therapists present the most updated information and new treatments to patients and their families. In these conventions families can see other people that suffer from fibromyalgia and get a better understanding on the difficulties their family member is facing.

The organisation's volunteers have participated in conferences of physicians, nurses and other medical team-mem-

bers and explained about fibromyalgia and the difficulties patients encounter in their daily life. This brings to better understanding of the team when they meet the patients. It has also published and through its web site made information available to all. The organisation has promoted non-pharmacological treatments for fibromyalgia, including hydrotherapy, yoga Tai Chi, physical exercise, etc.

The ASAF organisation does much more than the support of patients, *e.g.* involving in providing legal consulting and helping patients argue their case in front of National Insurance Institute (NII).

Being a member gives the organisation more power when approaching the establishment and can bring a real change *vis-à-vis* the medical insurance companies, Parliament and NII, which are more receptive when the organisation speaks on behalf of the patients. Most important, the organisation constantly advocates the idea that patients can and should change the way they live in order to cope with fibromyalgia and take responsibility over their illness.

Despite the inherent difficulties of operating a purely voluntary body, all members of which suffer from this chronic disorder, nonetheless members of the association have succeeded in disseminating the message, increasing awareness and advancing the rights of patients.

In the aftermath of an ASAF appeal, the Israeli supreme court has ruled on the necessity of including fibromyalgia in the Israeli national insurance institute

list of disabilities. Lectures on fibromyalgia are currently incorporated into the curriculum of medical students and the Israeli medical association has published national guidelines regarding the diagnosis and treatment of fibromyalgia (4). The collaboration between physicians, clinical researchers and patients has proven to be priceless, once it gets started in good faith.

Future developments are likely to bring about many changes, but patient organisations are not going away in the field of fibromyalgia. Even as diagnostic criteria continue to evolve and as precision-medicine holds the promise for personalised medicine and accurate sub-grouping and categorising the large group of individuals who currently carry the fibromyalgia label, chronic widespread pain is likely to remain a salient challenge for both medicine and society as a whole and within the boundaries of this challenge the voice of patients will rightfully require its place at the table. Let's keep talking.

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