

**Dystonia Europe 20<sup>th</sup> Anniversary Conference**  
**“Achievement and Hope”**  
**Edinburgh 2013**

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**An approach to Patient Advocacy**

Patient advocacy groups can play a central role in the diagnosis and management of dystonia. They can complement the work of medical professionals by addressing gaps in the medical process. Aside from core advocacy, three important areas are:

- **Outreach to the undiagnosed** Dystonia symptoms are suitable for online advertising. Using this route, 125,000 symptom searchers p.a. now come to our website and the proportion signing up for newsletters who first learn about dystonia online has risen from 10% to 30%.
- **Telephone support** The period between diagnosis and effective treatment can be deeply distressing due to uncertainty, pain, isolation, comorbidity with mental health problems etc. Clinics often lack the time and/or patient relationship to address concerns. Telephone support is therefore vital: used by estimated 65% of those with primary dystonia – 98% reported helpful, 75% helped with information, 76% helped emotionally.
- **Holistic dystonia management** Interventions such as physiotherapy, pain management and psychological support lack a solid evidence base for dystonia and provision in the UK is variable. But high percentages of patients report finding them helpful. Patient groups have an important role in promoting provision of and research into these treatments as well as supporting other coping strategies.

The Dystonia Society represents less than est. 1.5% of total UK dystonia healthcare costs. It is an affordable model and one that patients, medical professionals and patient-centred drugs companies across Europe might want to look at duplicating.