

HMSA

Hampshire Family Programme and Information Day

Points from feedback session

- There are not enough OT's in the county and at times they do not understand what hypermobility is
- Occupational health assessments over the phone are difficult
- Very difficult to get a speech and language therapist in Hampshire, people have to go private to get seen.
- Professionals at times tell patients and their families that they do not believe them, which is upsetting.
- GP's need to be more willing to do some research and work with Patients when they are not entirely sure what to offer for support. Patients have a lot of information and knowledge about their own condition and professionals sometimes forget this or patronise by goggling in front of patients.
- Currently only 6 physio sessions are offered and then the service is stopped. Six session is often not enough and the intention was originally that 6 sessions would trigger a review and not a stop on the services.
- Big recruitment issues with physio's in Hampshire
- There is a real need for a short term, easy access physio services that can be called upon in higher need situations. This would be a quicker intervention. Three month wait is too long. Even phone consultations would be helpful. Physio's also need some leeway in appointment times to be flexible.
- There can at times be very poor communication between professionals and patients and their families. Families feel that they are pinged around the system and never get anywhere as they are not listened to.
- There is a need for more pain management services in the county and more support groups for pain management.
- Integration is vital to the treatment of these conditions – as patients use many different parts of the system and feel like no one talks to each other.

My general comments

Really good event that was well supported and well run. The people that came were obviously very involved in the care of the person they were supporting and were very keen to learn more and get the support they wanted, I felt that many people that were fighting against the system to get support and were being thrown around the system by the NHS that doesn't quite know how to handle them.

Quote from me

It was a great day that really brought families of people that have to deal with hypermobility everyday together said Steve Taylor, manager of Healthwatch. We were proud to support the great work of this charity and hope that the NHS will listen to their voice as they try to improve the system.