

A report on the results of the Training & support programme at Coventry University

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“We felt on the outside of it until we got involved with the touch therapy.”

This was one parent’s comment after attending the Training and Support Programme (Cullen-Powell & Barlow, 1999©). For many parents, getting actively involved in the management of their child’s condition and becoming involved in their child’s care were key factors in participating in the TSP:

“We’ve been involved in a couple of trials with ataxia, but none of them has really been something we could all be involved in. They’re more medical trials with drugs and stuff, so we thought that as we could all get involved in the massage we’d give it a go.”

In addition, parents hoped that by learning a practical skill, such as massage, they could help relieve some of the symptoms (eg stiffness) their children experience as a result of ataxia.

The Training and Support Programme (TSP) was developed to provide parents of children with disabilities, chronic conditions, or illness, with a simple massage skill that they can use with their children in the home environment. A recent study of the TSP for parents of children with ataxia, funded by Ataxia UK, showed many benefits for both parents and children. Parents’ health and well-being had significantly improved after attending the TSP. Parents reported feeling less stress in their lives, were more satisfied with their life, and felt more able to contribute to their child’s health, care, and general well-being. Indeed, one parent became more ‘accepting’ of their child’s ataxia over the course of the Programme. In addition, practising massage at home had enabled parents to spend ‘quality time’ with their child:

“It gives us some quality time together. Because when you are working and have other children you don’t always get time to do nice things. It’s always doctors and hospital appointments ...”

One unexpected benefit was the development of a social network for some parents who had travelled to the same venue on the same day for the TSP. For these parents the day became a social event with lunch playing a major part in addition to the TSP! This social network was perceived as invaluable for parents: they valued meeting other parents of children with ataxia, but importantly, this ‘get together’ was seen to be of value for their children too:

“Going to the TSP, we met other families who had sessions that day, we got chatting, went for lunch. It was good to know them not only for us but also for our daughter as it made her realise she wasn’t alone and that there were other young children around who had ataxia.”

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Parents reported a number of physical benefits for their children: stiffness in joints eased after massage, fewer episodes of 'jumping legs', circulation and balance improved, activity levels increased and children were calmer, less agitated, more relaxed and generally appeared happier with lots more 'smiles'. Children themselves reported having less pain and better sleep. Children were reported to be eating better and for some children non-verbal communication improved.

Parents were asked about their favourite aspect of the TSP. This was clearly the 'one-to-one' 'quality time' spent with their children. It gave parents and children time to talk and 'just be' together, quietly, but with meaning. For children, their favourite aspect was symptom relief, particularly the reduced pain and stiffness and jumpy legs, as well as the overall calming effect of the massage:

"... I think it has helped him to relax more. When he goes to bed he normally just lays down and can't sleep and his legs are jumping and he did actually say that his legs weren't jumping."

Therapists delivering the TSP were considered to be understanding, supportive and flexible in meeting both parents' and children's needs. In fact, all parents expressed a desire for the TSP to be longer and to have some follow-up contact with the therapist and the Research Team. It was pleasing to hear that parents would continue to massage their children at home after they had completed the TSP and two parents were going to purchase a couch! One parent had started to use her newly learned skill on other members of the family as well as her daughter.

The improvements noted in this study for both parents and children are encouraging and also will add to the scant evidence of complementary and alternative medicine in the area of ataxia. We would like to thank Ataxia UK for supporting this study and to all those parents and children, and therapists taking part.

The Ataxian 150 2005:7

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