

Title: Feedback from Narcolepsy Peer Support Group

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Introduction

Narcolepsy is associated with significant psychosocial and functional difficulties in adults, which usually start in childhood. Psycho-educational intervention is recognised as a means of involving patients in their own care. We use peer support groups (SG) to address potential psychosocial problems in young people with narcolepsy.

Method

Evelina London Children's Sleep Unit has a cohort of about 140 young people with narcolepsy between the ages of 3 and 16. For over five years we have run biannual narcolepsy specific SG. The groups aim to utilise psycho-education and peer support to improve psychosocial adjustment and management of narcolepsy. Groups run for 3 to 4 hours, including breaks (breakout room for sleeps if required) and lunch. Parents and consultants meet for a Question and Answer session. Young people meet with the psychologists for a group discussion. The whole group then reconvenes and the young people feedback.

Results

Between 6-14 young people and 10-17 parents attend each cohort (in 3 year age windows). Feedback is collected via anonymous and identifiable questionnaires using scaled and open ended questions. Findings are shared with families. Groups are rated positively by both parents and children on categories including: enjoyment, narcolepsy knowledge, usefulness. The average score on questionnaires (figure 1) from recent groups was 8.5/10 for parents, and 8.3/10 for children. Comments from children and parents emphasise that they enjoy meeting other children with narcolepsy, and it helps to know they are not alone. Common problems (e.g. falling asleep on public transport to school) are discussed with solutions being suggested by families within each group.

Discussion

Groups are oversubscribed. Groups dynamically evolve according to feedback from previous meetings. Outcomes are very positive.

Peer support groups seem well placed to target psychosocial adjustment and narcolepsy management. We are increasing our capacity as well as exploring health economics of this approach.

Figure 1: Narcolepsy Peer Support Group Outcomes/ Category Measures

	Parent Scores	Child Scores	
Parent Questions	0....to10 rating - ve....to+ ve		Child Questions
1. Enjoyment of group	8.2	8.2	1. Enjoyment of the group
2. Learning about narcolepsy	8.2	7.7	2. Learning about narcolepsy
3. Helpful to talk about Narcolepsy	9.2	8.8	3. Helpful to talk about narcolepsy
4. New things to help my child	8.2	7.4	4. Learnt new things to help me with my narcolepsy
5. Recommend the group	8.2	8.8	5. Recommend the group
6. Enjoyed meeting other parents	9.5	8.9	6. Enjoyed meeting others with narcolepsy
Average score over rated outcome questions	8.5	8.3	