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Organising and hosting an annual family day for children with narcolepsy: the experiences of Sheffield Children's Hospital sleep team

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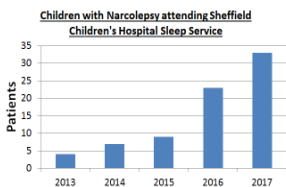
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INTRODUCTION

Figure 1: Increase in Referrals to Narcolepsy Service



The Sleep Service at Sheffield Children's Hospital (SCH) has experienced an increase in the number of paediatric narcolepsy referrals (Fig 1).

Families felt isolated and were spread over a large region in the North of England (Fig 2).

In order to provide additional support for these patients and their families, the sleep team have set up an annual 'Sheffield Narcolepsy Family Day'.

The aim of these events are to enable the families to interact, discuss their concerns, share ideas and keep up to date with the latest narcolepsy research.

Figure 2: North of England Spread of Children with Narcolepsy



AIM:

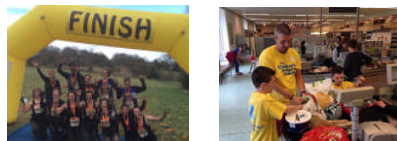
Here we describe the experience of organising three family days and summarise the learning points.

METHODS:

FUNDRAISING

- Each event has been funded by families and the sleep team doing a range of fundraising events; e.g. Mud Runs (Fig 3).
- Open Gardens
- Supermarket bag packing (Fig 4).
- Sponsored pyjamas at school days
- Focus group funding

Discounts have also kindly been agreed on venue hire and activities run during the family days.



Figures 3 & 4: Fundraising Events

PLANNING THE DAY

- Easy to access venue for region
- Venue capable of mixed usages
 - Talks
 - Workshops
 - Snooze area
- Mixed programme of talks, activities & workshops
- Invite families, teachers, sleep-related professionals



Figures 4 & 5. Activities at Event 2 & 3

EVALUATION

- Feedback forms completed
- Suggestions for future themes
- Timings of day & when in year



Figures 6. Obtaining Feedback

RESULTS:

- From a scale of 0 (not useful) to 5 (very useful) the average ratings for the three family days were (4.5/5.0 to 4.7/5.0)
- Lessons learnt and feedback-related suggestions from the family days are shown in Table 1.
- Developments as a result of the family days include:
 - Focus groups
 - Closed group Facebook page
 - Families meeting up for social events themselves



Learning Points & Top Tips

Planning the event well in advance, avoiding exam times, avoiding clash with Narcolepsy UK conference, adaptable venue for snooze area, talks & workshops
Relaxed, informal approach with times for chatting and meeting others in similar situation

Fun and interactive activities to keep children alert and allow them to bond (e.g. Pottery, board games, craft activities)

Keeping it positive – speakers who are positive (e.g. Teacher with Narcolepsy, child presenter with Narcolepsy on school life; workshop on nutrition, focus group activities for research projects)

At times separating parents / carers from children for age appropriate discussions

Sharing what works and making as much of the day family led.

Taking on board feedback and future suggestions (e.g. . For next year the suggestions have been: Transition; Medicines Update, Pottery session again which ran all day so children could dip in whenever they wanted).

CONCLUSIONS

- Holding a family day for children with a rare condition such as narcolepsy is beneficial as it enables children to meet others in a similar situation and for parents to talk to each other and professionals. We have had really positive experiences from these Family Days and as staff have also learnt a lot from our families.

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Need to add in other thanks etc hotels/ Evelina / Caroline Lee Ceramics who ever else helped the events happen