TIRED ALL THE TIME

The impact of sleep difficulties on families with disabled children

family fund
helping disabled children

Contents

AROUND THE CLOCK CARE

12:00am
“Crawl into bed and try to get some sleep.”

2:40am
“Jade wakes and screams that her leg hurts so I get up and massage it for her.”

5:00am
“Jade wakes again, a strand of hair has fallen across her face and into her mouth.”

6:30am
“Woken by Jade calling ‘Mum’. I stumble out of bed and try to function.”

7:30-9:00am
“Gulped cup of tea, showered Jade, sorted shower tray from wet room, cooked breakfast and slowly fed Jade so she doesn’t choke.”

11:45am
“Occupational Therapist arrives to talk to us about equipment for Jade for summer play scheme.”

12:30-6:00pm
“Prepare lunch, feed Jade, take her to her room to use her computer. Jade asks for the toilet three times which includes a hoist and sling with straps to manage. Then we nip out to the shops to get some air and stock the cupboards.”

7:30-9:00pm
“Jade needs toilet again, dad takes her off so I can spend some time with my son and his homework. Load dishwasher and get Jade ready for bed.”

11:40pm
“Jade calls me, she has pushed her covers off again and is getting cold so I tuck her in again and go back to bed.”

MEANS YOU’RE TIRED ALL THE TIME

Foreword

For forty years the Family Fund has provided essential grant making support to families raising disabled or seriously ill children across the UK. Through our work and engagement with families, we hear first-hand about the challenges that parents and carers face every day. The physical, financial and emotional challenges that come with being a parent are even greater when your child has a disability or serious illness.

We help families with grants that will make a real difference to their lives and improve their well-being, items such as washing machines, bedding, clothing, computers and support with hospital visiting costs can create a significant and positive impact. But what happens when the only thing that will make a difference to a family is sleep?

Sleep is vital for us all. It replenishes our bodies, gives much needed rest for our minds and enables us to function. Without sleep, we can become ill, irritable and worn out. Many of us will relate to those long sleepless nights, walking the floors rocking small babies, hoping that sleep would come soon. For many families of disabled children, sleepless nights continue on relentlessly, year after year and sometimes well into adulthood.

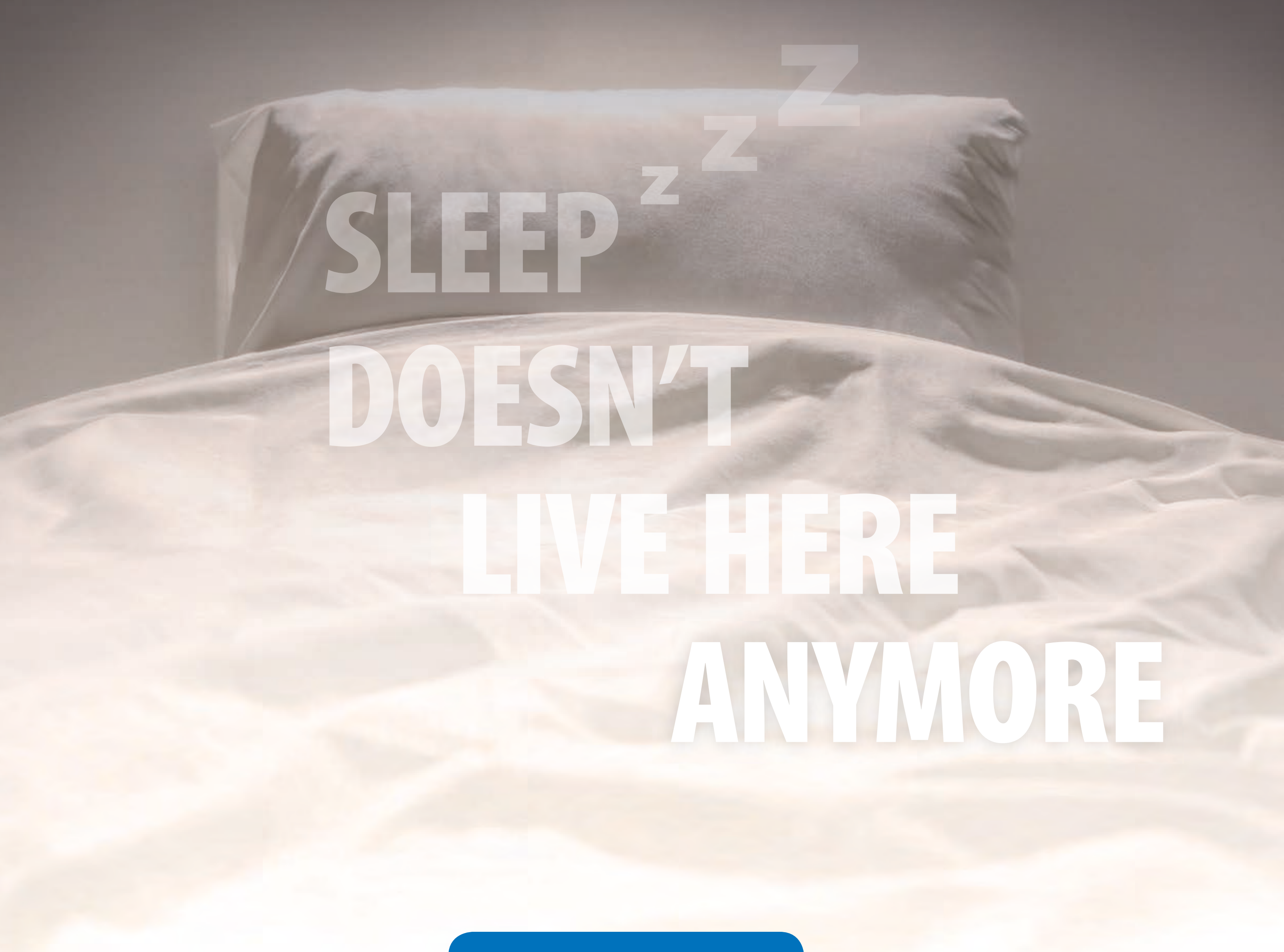
'Tired all the time' captures the experiences and feelings of parents and carers raising disabled or seriously ill children or young people across the UK. We asked parents and carers to speak freely about their routines, the care they provide for their children, and the support available both locally and nationally. The report does not just contain statistical data but is filled with their voices.

Cheryl Ward *Chief Executive*

The very high response rate to our 'ask' reflects the intense desire for wider recognition of the impact of sleep deprivation.

We hope this report will help raise awareness of the enormity of the difficulties families face and encourage policymakers to look at the additional support needed. We thank every parent and carer who took part and gave us a valuable insight into night time for them and their families.

Cheryl Ward
Chief Executive



SLEEP DOESN'T LIVE HERE ANYMORE

"He wakes up several times every night, sometimes because he has wet the bed, other times because he is very active. Dad has to get up with him as he needs constant supervision"

"We are tired all the time and some days, can barely function."

"My son is ten and will not sleep anywhere except with me and never has. He cannot sleep alone or be in any room alone."

"My depression gets worse."

"As a widow I am sole carer. Lack of sleep has nearly killed me. I am tearful and constantly exhausted."

Background and context

Sleep issues are not a new phenomenon for families raising disabled and seriously ill children, but it is an area that is often rarely addressed or spoken about. Family Fund has supported thousands of families with grants to help make sleep better. Beds, bedding, sleep monitors, black-out blinds and sensory toys are just a few of the items provided to help families gain a better night's sleep. Our Advisers report that families often do not mention sleep difficulties at their visits unless prompted. Parents and carers have endured lack of sleep for so long, and are often too busy coping with other challenges in their lives to seek support for it.

In 2005, the Family Fund supported the Handsel Trust in undertaking a piece of research with 375 families helped by the Family Fund. The results showed 65% of families received no help with sleep difficulties, with information not reaching those who needed it. More recently, Contact a Family in its report, 'What Makes our Family Stronger', stated that 60% of families responding to their survey reported that their opportunity to get a good night's rest was poor or unsatisfactory.

In 2012, the Family Fund, with the help of its team of Advisers, wanted to know what the key health issues were for families of disabled children.

The top three concerns were:

- Advice on behaviour management
- Effects of sleep deprivation
- Access to mental health services for children and parents.

Sleep deprivation and sleep management often affect a child's behaviour and mental health, so the three issues are interwoven. A subsequent article featured in The Guardian listed the findings, provoking a huge response, and parents were keen to know how the Family Fund could help. This response is a result of pleas from families and practitioners who wanted evidence to raise to commissioners and key professionals.

> "One child needs their nappy changed; one sleeps lightly; neither child can bear to sleep alone so dad sleeps with one and mum sleeps with the other."

Throughout the UK there are services providing excellent support and practical guidance on sleep issues, including those provided by Sleep Scotland, Scope (Sleep Solutions), Cerebra, SleepSense and The Children's Sleep Charity. A wealth of knowledge also exists with locally based sleep practitioners and consultants. Sadly, there are lots of families who are still struggling and we hope that this report will encourage a more holistic approach to sleep management to be developed across the UK.

This report comes at a time of change in legislation and policy for families raising disabled children. We must not forget that the lives of disabled children are broader than their educational attainment. Without sleep, disabled children, their siblings, their parents and wider families, cannot achieve, attain and lead healthy and happy lives.

Parental health is hugely affected by lack of sleep. Sheer exhaustion causes problems with mental health, physical health, memory and esteem.

Methodology

The findings from this report were derived from a survey of 2077 parents and carers from across the UK who completed a survey and shared their views.

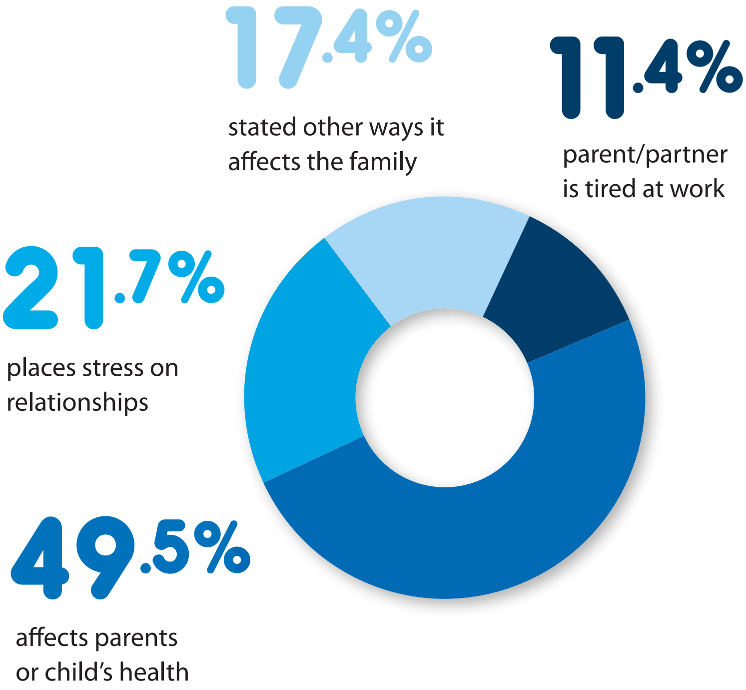
The questionnaire was complemented by face to face discussions with families during home visits with our Family Fund Advisers. 92 families took part, their responses and key findings are summarised in Appendix 1.

93%

of parents reported being up during the night with their children.

Key findings

Q1. What is your greatest worry about your child's sleep and how it affects you and your family?



> "I have had a seizure through sleep deprivation."

> "Impacts on my mood as well as my health - have been hospitalised once due to exhaustion."

> "The less sleep my child gets the more stressed and short fused he gets, causing more 'meltdowns'. We constantly struggle to get through a working day and fall ill more often from lack of sleep. We also snap at each other and are less patient when we are sleep deprived."

> "I have not had a full night's sleep in 11 years and am exhausted."

Q1. continued

Lots of parents are very concerned about their child's health during the night. With anxious nights spent worrying that blood levels may drop, their child might have a seizure or even worse, their child might die. Parents are also worried about their child's safety, if their child were to wake and not be heard would they cause harm to themselves or others?

> “ *When she wakes up in the middle of the night and doesn't go back to sleep, I worry that she'll leave the house without our knowing. I'm single and worry I might not hear her.* ”

Sleep issues not only affect the child but other children in the family too.

> “ *It not only affects me and my son (who has a disability) it affects his two sisters, their lives and education. Going to school tired each day because they've been woken up several times overnight.* ”

15% of families specifically mentioned concern for siblings. This was about both sleep disturbance, and being too tired to give their other children the support and attention they need during the day. There is also added pressure on families who would like to return to work but are unable to.

15%
mentioned concern for siblings

> “ *It makes it impossible for me to contemplate going back to paid work.* ”

There are dangers of working whilst tired when a family relies on income to survive.

> “ *Dad has a job that could result in a serious injury if distracted, both boys are tired, and I have health issues which make me tired anyway.* ”

Families talked about the effect sleep disturbances has on their wider lives, in their homes and communities. Problems with neighbours is just one such example.

> “ *The neighbours threaten to call the social services and hammer on the party wall and front door if there is a slight sound after 10pm.* ”

There is constant stress placed not only on relationships, but also on the ability of families to function and look towards the future.

> “ *It disturbs the whole family, so his brothers can't function as well at school, and both parents are constantly tired and never have time in the evenings to sort things out, talk, make plans.* ”

But more than this, the continual pressure of going without sleep means parents have to consider making very difficult choices,

> “ *After 14 years without a night of solid sleep I wonder how long I can continue to care for him.* ”

What also became clear, through the lack of sleep and dire need of rest, is an amazing understanding by parents of why some children cannot and will not rest at night. As one parent says:

> “ *I feel that now he is 13 this sleep pattern will be the blue print for his adult life and I obviously understand that he prefers to be awake in the middle of the night for the elixir of life or, as he calls it, 'quiet'. He is one of seven people living in our little house and at his enormous school, there are just short of 2000 pupils. So for him, he needs this sanctuary of the night, being awake.* ”

Lots of respondents were very concerned about the effect on the academic ability of their disabled child as well as their brothers and sisters when tired. 16% specifically mentioned this as an area of worry for them, giving examples of children falling asleep in school or bad behaviour in school because they were tired. Parents were concerned that their children were unable to reach their academic potential because of the effects of limited sleep and also arriving late for school.

A recurrent theme was the worry of driving when tired. Many parents of disabled children rely heavily on being able to drive in order to get their children to school and to numerous medical appointments. For some children, the use of public transport is just not possible because of their physical or behavioural difficulties. Driving when tired is hazardous and parents worry about what might happen.

16%
concerned about academic ability of their disabled child and siblings

RUNNING ON EMPTY

over 10% of families reported being tired at work which added to the pressure to maintain a job.

"Has effect on my health after a few weeks; I'm both shattered driving and working."

"We are all tired constantly. I can't drive for long as I'm too tired."

"My partner drives for a living if he's tired at work it could endanger lives."

"Both my child and myself and my husband are unable to function normally during the day. This is especially concerning when we have to drive any distance."

Q2. Does your child wake and/or need you to help them during the night?

Parents shared the erratic nature of their child’s sleep difficulties and the unpredictability of how long or how often they might be up on each occasion. Responses ranged from 10 minutes to five hours, with some parents reporting they were up all night with their child on a regular basis.

Similarly the kinds of difficulties reported also varied hugely – some children dropping off to sleep well, but then waking around midnight for the rest of the night. Others were awake for a long time and fell asleep in the early hours, only to find it very difficult to wake for school the following morning.

“He gets up and gets into bed with us or his siblings - he is now 17 and 6 foot1” which disturbs whoever he decides to share with. He often cannot get off to sleep and just sits in his room or mine!”

“She can wake every hour or not even allow me to leave her all night.”

“My child only sleeps for 2 hours before midnight and from 5.00-6.45am. The rest of the time, I have to be with her to make sure everyone else in the house gets rest.”

“This changes with health, up to age 4, sleep was only for 2-4 hours max, used to sing 1,000 green bottles hanging on the wall! Now it’s 6-8 hrs with 1 or 2 turns in the night unless she is unwell.”

“Have twins both with special needs both wake three four times a night.”

“Our daughter, with Down’s Syndrome, will wake once in the night and climb into our bed. One of us will swap with her and use her bed for the rest of the night. She usually sleeps well but fidgets. Once or twice a week, she will get up several times for the toilet or be unable to get back to sleep properly. Our son, with cerebral palsy, will usually wake once and needs reassurance and someone to stay in the room/ bed before getting back to sleep.”

“Often awake on and off until about 4am then sleeps til 6am then up. Total time up, 4 hours.”

“Worst night was when son did not go to sleep at all. He was awake from 8am Friday till 11pm Sunday night.”

“5-20 times from10-30 minutes at a time.”

“Depends. Feeding pump occlusions, pump to be turned off, meds to be given, tube to be flushed, then several toilet visits. If vomiting, bed to be changed, child to be washed and changed. Then add in nightmares, anxiety and general reduction of sleep needs. Anything from half an hour to several hours.”

“Can be 3 nights or more a week and can be from 1am onwards, fully awake.”

Q3. When you attend to your child in the night, is it to provide care, for example, medication, turning, suction and/or to provide comfort and reassurance?

A staggering amount of personal care is provided by parents during the night. Over 60% are providing comfort and reassurance or as one parent put it *"love and cuddles."* However, a significant proportion of parents are also providing complex medical support to their children. The medical procedures, monitoring and management include:

- Turning
- Suctioning
- Providing medication
- Checking blood levels
- Oxygen
- Cpap machines
- Managing seizures
- Pump feeds
- Pain relief
- Massage.

> *"She has severe cerebral palsy - sometimes she needs re-positioning to make her comfortable, or her hair is in her face, or duvet has come off and she can't pull it back over her. Sometimes she chokes and struggles to breathe properly. When she is unwell she can be awake most of the night. Other times she wakes frightened and needs reassurance."*

> *"To remake her bed, to make sure she is not getting up to anything dangerous. She has, in the past got hold of scissors and cut her own hair. To try and keep the noise down so she does not disturb her sisters. To help wash and change when she has accidents. To change the bedding. To clean the bathroom, if she has smeared on the walls and surfaces. To help her if she is in pain. The list goes on and on."*

> *"We provide comfort, reassurance and ensure he is safe. We have to stay awake during the whole episode as he has life threatening nocturnal seizures. These seizures occur in the early stages of sleep and when he is coming out of sleep. We have to keep a monitor on all the time and he is extremely loud during the night!"*

over 60% are providing comfort and reassurance

> *"Just to check on her. She can't be trusted even though she is fourteen. She has no idea about dangers. Has put her hand in the deep fat fryer before, poured drinks, gone in the lounge, touched things and got nail varnish out. You name it, she has done it."*

Many parents are also providing other types of personal care for their children – changing bedding, clothing, bathing and showering their children when they have accidents or have vomited. For a proportion of parents, it is a combination of all of these types of care.

The words *"keeping my child safe"* were repeated numerous times throughout the responses. Many parents attended to their child in the night to ensure that they were not causing harm to themselves, or other family members. There were also worries about causing damage to property and belongings.

There is a sense throughout the feedback from parents, that most do not get deep and restful sleep, because they are always on high alert to respond to their child's needs. Hence the quality of sleep many parents and carers are getting, when they get it, is likely to be extremely poor.

Q4. Does your child share a room with a sibling or need to sleep with a parent or carer during the night?

22% of parents reported their child sleeps in their room on a regular, if not nightly basis. Many reported putting their child to sleep in their own room, but they have to settle them in their rooms during the night to ensure they do not disturb siblings or other family members.

17% of families have their disabled child sharing a room with a brother or sister.

> *“Yes, with a sibling. I worry about him as his sleep is often disturbed and it breaks my heart to see him tired.”*

“Used to sleep with sibling until sister developed mental health problems as a result of constantly being woken.”

“I gave up my bedroom to separate my son and daughter.”

“We’ve taken out a huge loan on our mortgage to build an extension so she can have her own room.”

“We have our housing benefit limited. We have a bigger house than housing benefit allows as we have two children who cannot sleep together due to their additional needs.”

But the picture is not so clear cut. A lot of families said that their child used to share a room but that they had to take drastic action, to ensure the health of their other child or children.

Overcrowding and the lack of understanding from housing departments about the consequences of children sharing a room was a common concern. Parents also talked about the other siblings being cramped, sharing a room because the disabled child has to have their own room.

> *“I am his Nan bringing him up and we share a bedroom because of overcrowding.”*

Families spoke about the financial implications of having to move to bigger, more expensive properties so that children have their own rooms to get the best rest at night time. Some parents reported extending their current homes so their disabled child has a bedroom of their own.

“He used to share, but it disturbed his brother, so I had to convert the shed to provide a separate bedroom.”

“Used to sleep with sibling, but woke too often at night so now has own room. Sibling now sleeps downstairs.”

Q5. Have you asked for any professional advice about your child’s sleep difficulties?

The responses were mixed in how useful they had been. Some reported that although professionals had been kind and listened, they were really unable to provide any practical solutions.

> *“ I have asked over and over and over since he was six months old. We always get a sympathetic face but no help. ”*

A number said practitioners were offering the same advice that they would to parents of children without disabilities, which really did not work for children with additional needs or health concerns.

> *“ I asked a health visitor, who advised to leave him to cry. This might be feasible advice with a normally developing child, but impossible with a distressed disabled child when you can’t be sure of reason for waking and when reassurance is so vitally important to them. ”*

Others had benefited enormously from the help of voluntary organisations and/or support groups.

> *“ Sleep Scotland helped 5yrs ago and improved sleep by at least 80%. ”*

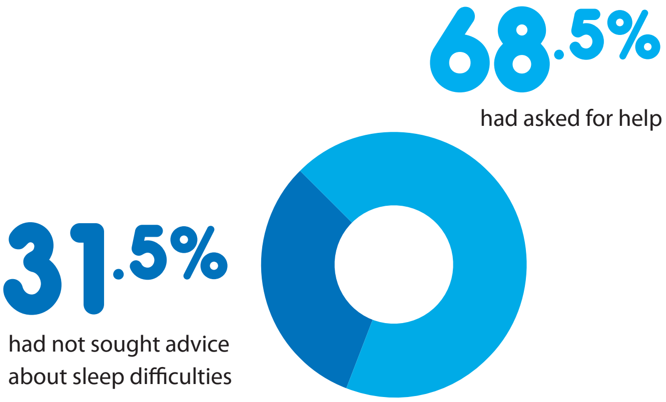
> *“ Attended sleep seminar provided by Cerebra, very helpful, they have a sleep therapist who will help all they can. My child’s doctor just offers sleeping meds which I don’t want. ”*

> *“ Sleep solutions training session. That helped a lot. ”*

> *“ The best advice has come from other parents who share the same difficulties. ”*

It was clear that families also had very mixed support from health and social care staff, some good, some not so helpful. Some families are clearly exploring numerous avenues and trying different routines to rectify the sleep issues. What is of concern is the fact that sleep difficulties are not taken seriously by some professionals, and the detrimental effect this has on exhausted parents.

> *“ GP dismissive (laughed), Community Paediatrician said too young for melatonin and will review in 6 months, Health Visitor said she will speak to Child Psychologist. ”*



> *“ I spoke to my Specialist Health Visitor - she clearly didn’t really believe me when I said how many times she woke every night - she told me it would get better as she got older - not very helpful at the time! She didn’t suggest any other sources of support. ”*

Almost a third of families had not asked for help at all with regard to their children’s sleep difficulties. The following quote is probably a good indication of why not.

> *“ Melatonin was prescribed at one stage. Child and Adolescent Mental Health Services has stopped prescribing. They said the GP ought to refer to a sleep disorders clinic 25 miles away. There are too many other health issues with higher priority so we haven’t organised a referral yet. ”*

Lots of parents who did seek help were often dismissed with comments that this is something that is just part of their child’s disability or something they need to accept and get on with.

Professionals/services consulted by those who had asked for help:

- Neurologist
- Paediatrician
- ENT[*] Consultant
- School teacher/nurse
- Learning Disability Nurse
- GP
- Social Worker
- CAMHS[**]
- Health Visitor
- Portage Visitor
- Pain team
- Voluntary Organisation
- Dietician
- Occupational Therapist
- Physiotherapist
- Psychologist
- Psychiatrist
- Alternative therapist

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[*] Ear, nose and throat consultant [**]Child and Adolescent Mental Health Service

> *“ Asked GP. Told it’s common with autistic children. ”*

A number of families also felt like they had tried everything, asking for help and support, but that nothing had really changed for them at all. Some families are just too tired to read some of the written advice they had been given.

> *“ Have tried everything possible but, at the age of almost 9, we have accepted the fact that he is going to visit us every night. If we lift him back, he turns up again. He is too heavy for me to lift and he isn’t awake when he comes in so it’s easier to leave him there! He has trouble falling asleep at night, it’s usually 10pm so we are just relieved at whatever rest we get!. ”*

> *“ I’ve asked all professionals from GP to school and have tried over 50 different sleeping routines, daily action plans, diets, medication. Nothing works. ”*

There is also a sense of families having to battle for a really long time, often years in some cases, to get help.

> *“ We have been asking for many years for help with sleep problems. Only after eight years we have been given some help. ”*

The biggest single response to what advice had been given was for medication. **30% of families had been given medication for their child’s sleep difficulties**, but there were mixed feelings about whether their child should be taking it. There were lots of comments about feeling that the system had failed their children by not trying to find the root cause of the sleeping difficulties. Some children refuse to take medication and some find that it either did not work well for them, or that its effects were intermittent. There also seemed to be little in the way of clear protocols about at what age sleep medication could be trialled. For example, two respondents had each been told, at aged four and aged 11 their child was too young for medication.

> *“ We had to request sleeping medication for the worst nights as we couldn’t cope with the severe lack of sleep we were all getting. However it took 18 months of fighting to get them. ”*

Lots of parents are still struggling to find advice that works for them, or indeed know where to go for help.

> *“ I have no idea who to ask, there is a lot of advice and all kinds of help for autism when dealing with day time issues (for example, in school or out and about) but I would like to know more about night time. ”*

> *“ My son hits, spits, kicks, swears and throws things when he get over tired, meaning he gets too stressed to sleep. He’s on three different sleep meds, but some nights we still only get three hours sleep! ”*

> *“ Was told there was little they could do for him, suggested I work less hours and sleep during day (can’t afford that). ”*

“Been there, tried it all...
Nothing works for us.”

Conclusion

The voices of parents make powerful reading and the strength of feeling from those that took the time to tell us about their lives should not be underestimated. Sleep deprivation can impact on children’s resilience and parents or carers capacity to cope. It can affect the whole family’s health and wellbeing with long term consequences such as limiting opportunities in education and employment. Families need clear support and understanding, not just from health and social care professionals, but also from housing and welfare organisations. Many of the respondents to our survey were in crisis due to lack of sleep.

There are two distinct areas. Some children are not sleeping well due to medical needs or interventions which are required throughout the night. These are vital and will continue to interrupt the sleep of disabled or seriously ill children and their families. Secondly, there are also those children and young people whose sleep is interrupted because of behavioural issues. All of these families require a range of support for management, routine, medication and equipment. Some will also need a break from caring and/or a night sitting service to be able to continue supporting their families.

Families need three things:

1. To be listened to, believed and heard when they talk about sleep difficulties.
2. Their concerns are acted upon at an early stage.
3. Timely and regular support, not just one consultation, as sleep deprivation is often not a short term problem.

Actions could make a difference

- Sleep difficulties need to be given a higher priority by health, education and social care professionals and included in relevant needs assessment processes and frameworks.
- Families need to be informed about clear pathways to accessing sleep advice, support and practical help at an early stage. This is a multi-disciplinary issue, families should have timely responses to identified needs, co-ordinated by a lead professional or keyworker.
- Sleep services should be listed in the local offer (England) and listed in signposting services for families with disabled children in local areas. Families should know how, where and when to access such advice and support services.
- Sleep deprivation in families of disabled children should be included in the professional education and training of health and social care professionals, such as GPs, Social Workers, Teachers and Health Visitors. Professional bodies/associations and providers of professional training should ensure the impact of sleep deprivation is understood by professionals within relevant disciplines working with families of disabled children aged 0-19.
- Families who need it, should have access to good quality short breaks and/or nursing care at home. Commissioners and policy makers should understand the health and financial impacts and benefits of providing such key services.
- A commitment from local authorities, health authorities and integrated children's services to resource sleep support for parents of disabled children, and to commission training for health and social care professionals so families' needs are clearly understood and met.
- Families need access to clear and relevant information and joined up services so they are aware of available resources to help their child. Some solutions can be quite low cost, yet very effective. For example, sensors used in the care of dementia patients can be effective in alerting parents when a disabled child/young person is wandering at night.

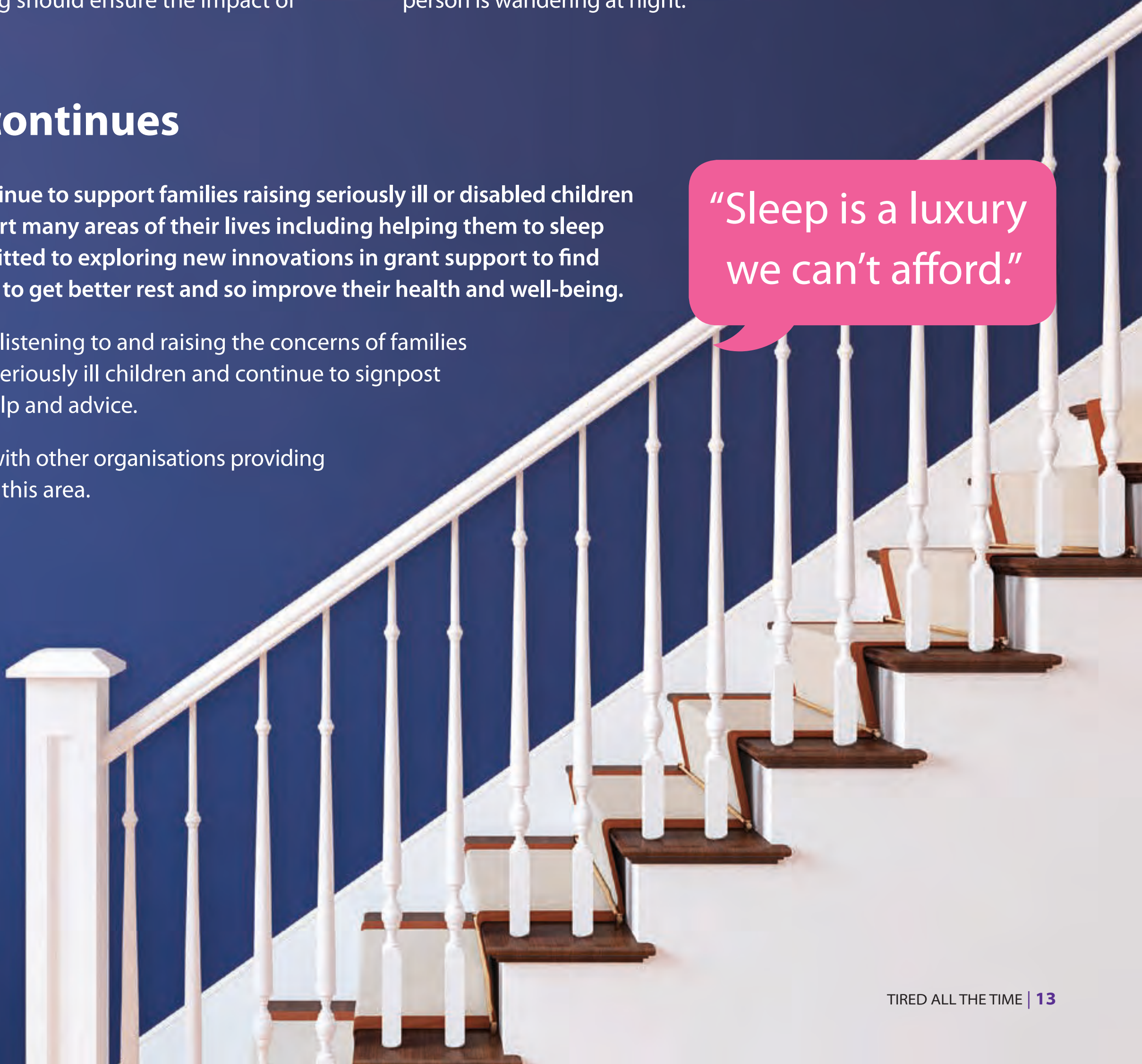
Our work continues

Family Fund will continue to support families raising seriously ill or disabled children with grants to support many areas of their lives including helping them to sleep better. We are committed to exploring new innovations in grant support to find solutions for families to get better rest and so improve their health and well-being.

"Sleep is a luxury we can't afford."

We are committed to listening to and raising the concerns of families raising disabled and seriously ill children and continue to signpost them to sources of help and advice.

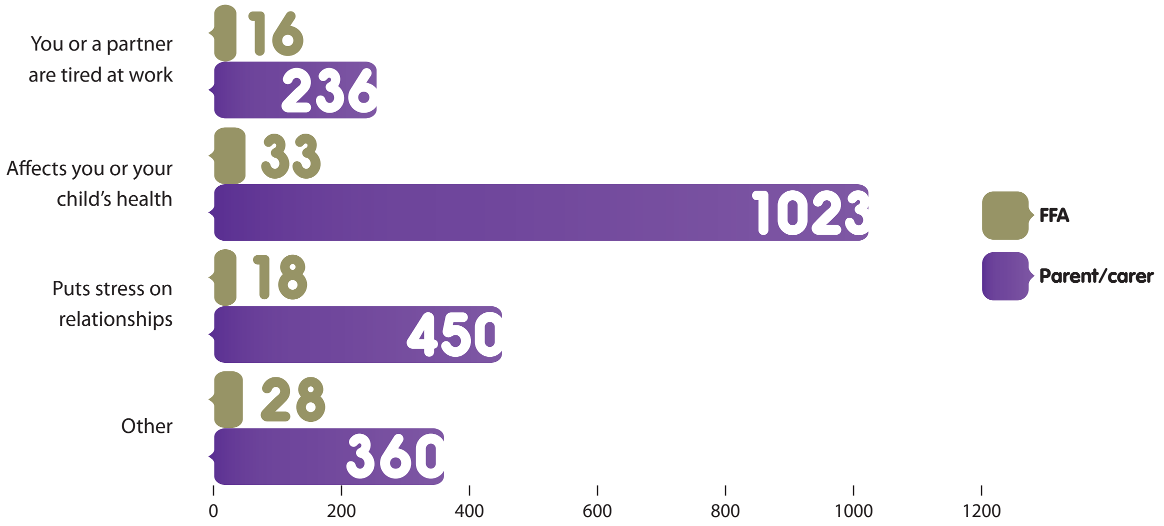
We are keen to work with other organisations providing support to families in this area.



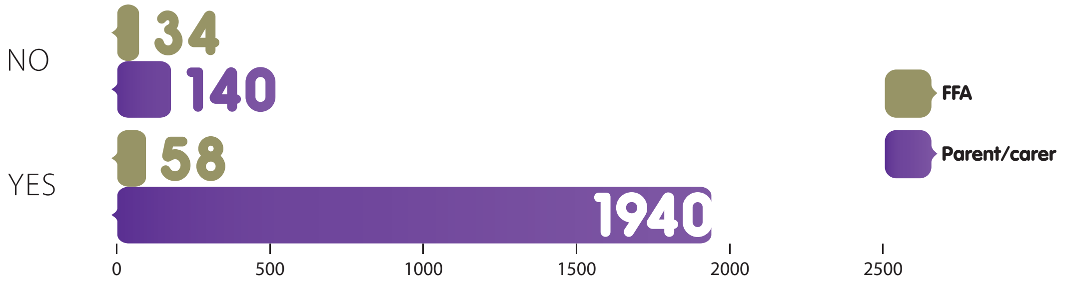
Appendix 1

Responses from parents/carers and Family Fund Advisers(FFAs)

1. What is your greatest worry about your child's sleep and how it affects you and your family?



2a. Does your child wake and/or need you to help them during the night?



2b. How often in total throughout the night? From those that responded:

	Once	Twice	Three	Four	More than four times
Parent/carer	15	18	26	10	29
FFA	17	10	9	13	14

2c. How long are you with them throughout the night? From those that responded:

	30 mins	1 hour	2 hours	3 hours+
Parent/carer	19	24	18	46
FFA	3	13	6	11

3. When you attend to your child in the night, is it to provide care, for example, medication, turning, suction and/or to provide comfort and reassurance?

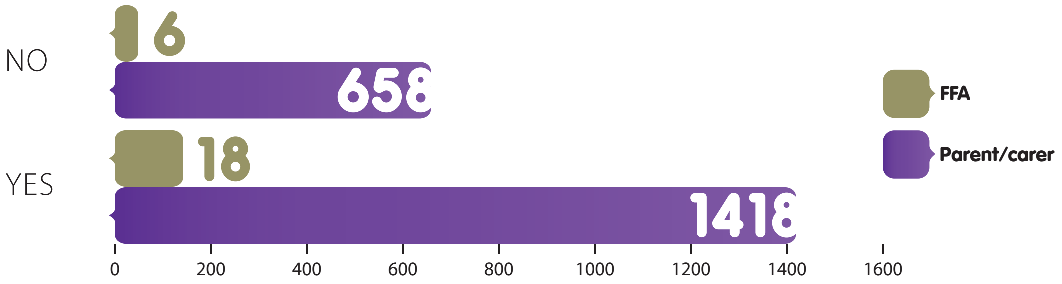
Some families answered more than one category in their response.

	Comfort/ reassurance	Care	Toileting/ nappy changing	Changing bedding/ clothing/ washing	Turning or repositioning	Provide suction
Parent/carer	1405	493	195	146	168	38
FFA	38	15	8	7	1	1

4. Does your child share a room with a sibling or need to sleep with a parent or carer during the night?

	Yes, child sleeps with parent/carer	Yes, child shares with sibling	No
Parent/carer	450	360	1267
FFA	28	13	0

5. Have you asked for any professional advice about your child's sleep difficulties?



If yes, who have you asked?

	Family	FFA
Paediatrician	134	8
Neurologist	9	
School	14	
Sleep clinic/counsellor	107	
GP	77	
Social worker	28	
Pain team	4	
Physiotherapist	11	
Community Nurse	33	
Health visitor	48	
Psychiatrist	13	
CAMHS	60	5
Psychologist	36	
Consultant/specialist	65	
Occupational Therapist	25	
Voluntary organisation	71	5

Appendix 2

About us

family fund
helping disabled children

Over 64,000 families across the UK raising disabled or seriously ill children were helped by the Family Fund in 2012/13, with grants for essential items such as beds, bedding, clothing, computers and much more.

It can be a struggle financially, emotionally and physically for families raising a disabled or seriously ill child. Families tell us that a grant can often be a lifeline, changing their lives significantly. We know the difficulties families face as they talk openly about how our grants have a huge impact. Every year we receive tens of thousands of messages from families who want to relay their thanks, and describe the difference we have made to their family's well-being.

We have been supporting families raising disabled and seriously ill children for 40 years and continue to help more and more families each year. Our 200 Family Fund Advisers visited over 9,400 families in their home during 2012/13 to talk through their application face to face, providing essential help, support and advice on local and national support available to them.

With a team of 60 staff based across the UK, the Fund received and reviewed over 77,500 applications last year.

The need for our help continues to grow as every day, new families come to us for support. We remain grateful for the grants we receive from the four UK governments and private donors who see the difference we make and the support that is still essential to families raising disabled and seriously ill children.

We know we can do more and we are committed to finding new ways to support even more families.

supporting families raising disabled or seriously ill children for over

over
64,000
families helped
in 2012/13.


Edinburgh 2012

family fund
helping disabled children

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Family Fund Trust for Families with Severely Disabled Children.
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