2023-07-16

Our children are our greatest asset and our future

We hope to help schools spot signs of narcolepsy by giving them the knowledge to think laterally if a child is perceived as ‘lazy’, not engaged, always sleepy. These things may lead to the involvement of Social Services . We were recently involved in a situation where a teenager was placed on a child protection register because of lack of attendance at school because she was just SO sleepy all of the time. Our involvement led to the order being removed and praise from the Chair of the committee hearing this case and absolution for the family. This was traumatic for child/family/all involved and may have been avoided if there were a better understanding of how this illness affects people. The waiting lists for diagnosis are long so the sooner something is spotted the quicker diagnosis is likely.

Narcolepsy UK can provide Information sessions to schools, at no cost, just an hour of your time. We can explain how learning for a child with narcolepsy is hard as they suffer micro sleeps and lose parts of a lesson thus losing cognition. They may be called ‘lazy’, or

Parents may be considered lacking, or there may be suspicions about home life – there are just so many aspects to this Disability that we are using the power of World Narcolepsy

Day to bring this to the attention of as many schools/educational establishments as we are able to reach *with your support, thank you.*

Narcolepsy UK is not funded by the NHS (despite their staff referring patients to us), has no regular source of income – we are reliant on the kindness and support of others otherwise we could not continue to offer our services freely. We are totally Inclusive. To 23-06-23 we have assisted 2304 via Helpline services alone.

We support people of all ages, all walks of life, are totally inclusive offering a range of services to a person with narcolepsy. This support extends to family members, friends, educators, employers, housing providers, basically a client asks for help and we will either --find that within our knowledge base or signpost. We regularly support children with DLA applications and over 16s’ with Personal Independence Payments, Students with DSA applications, and to end of June 2023 have helped clients gain over £700,000 in benefit awards alone. We help secure adaptations to homes and moves to safer housing. We help employees with reasonable adjustments in the workplace. I could go on!

Will your school help us continue our services by supporting us on World Narcolepsy Day 22-09-2023 by allowing pupils (and staff) to take part in CRAZY HAIR DAY – much like non uniform day – suggested donation £1 per pupil taking part (see poster for publicity) it is as simple as it says – do something ‘crazy’ with ones hair !!!

Cont/…2

TO EXPLAIN TO PUPILS why this is happening and why we ask for support

People can go to sleep at random times during the day yet cannot sleep properly at night. Their sleep/wake cycle has been damaged meaning they have Excessive Daytime Sleepiness and Insomnia at night. They also have crazy dreams which can be very scary (Look up hypnogogic and hypnopompic hallucinations) and some times those dreams occur during the day as well. A symptom of narcolepsy is cataplexy which is generated by heightened emotions and can lead to people falling down, appearing to have fainted, where they cannot move or speak for a short period of time (seconds, minutes) and recover quickly. This scares people and is often caused by something funny/laughable – it is strange and often not recognised by doctors/nurses.

OUR AIM is to raise awareness of this illness in order to aid people to think laterally if any or all of these symptoms arise in someone they know.

The NARCOLEPSY UK HELPLINE may be consulted about such matters and although we are not Doctors we do have ‘lived experience’ of this illness and can assist in helping persons obtain referrals to a Sleep Centre. There are several specialist Paediatric Centres throughout the UK which also support centres of learning as well as their own patient.

Our HELPLINE is pleased to receive calls from anyone interested in learning more.

We are not manned 24/7/365 but leave a message and we **will** call you back

0345 4500 394

Feel free to contact me with any queries and to book your Information Session

Yours faithfully,

Nicola Rule (mrs)

Operations Manager

Nicola.rule@narcolepsy.org.uk

07920 650 552

