Frustration, anger and irritation

The emotional impact of Narcolepsy

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THE EMOTIONAL IMPACT OF NARCOLEPSY

From a mix of personal and professional perspectives I discuss:
- Different types of emotional responses.
- The reasons behind some differences
- Management of emotions as, support & some ideas on what helps

I welcome questions and discussion throughout.
THE EMOTIONAL IMPACT OF NARCOLEPSY - DISCLAIMER

I am a father of Freya (now 21) who was diagnosed with Narcolepsy and Cataplexy at age 11 (during year 7)

…and a child care social work professional with 37 years experience working with children and families

All medical comments are of a general nature and therefore you should consult your medical advisers or other health care professionals regarding treatments
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Why I am interested:

I noticed that children had particularly strong – sometimes violent outbursts.

I noticed that these appeared to abate over time

I became inquisitive
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Three significant types of emotional responses. Understanding these is a key to understanding how to respond or manage them.

Some get better (or can do with help)
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1. Affective responses
2. Direct responses to tiredness
3. Neuro-psychological impacts of Narcolepsy
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Affective responses - 1

- feelings of upset, anger, why me? Denial, sadness etc.
- similar to other responses to illness or life changing events
- could be considered as a traumatic event similar to bereavement and loss (loss of expectations...loss of role...loss of ability to work/study etc.
- if untreated can be problematical in itself
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Affective responses 2

- treatment is support – or “talking” treatments
- treatment objectives would be about coming to terms with the condition
- if acute it may need medical intervention...but:
- tends to get better with time and treatment
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The direct effects of tiredness

- Extreme irritability and frustration
- Some effects similar to affective responses (anger that you can’t do or complete tasks or concentrate & etc)
- Particularly notable at times of greatest fatigue
- …or after waking

Cannot be directly treated – but can be understood and managed to an extent by good sleep hygiene/routines/managing naps and other good medical regimes
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Neuro- psychological impacts of Narcolepsy
The impact of the damage to the brain caused by the auto immune attack

The parts affected are central to our emotional regulation and responses
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Neuro-psychological impacts of Narcolepsy

Symptoms (in children):
- Behavioural outbursts
- Self harm
- Head banging
- Screaming
- Physical and verbal attacks on loved ones
- All very unregulated emotional responses – very similar to “terrible twos”
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The part of the brain affected and causing Narcolepsy is a part of the Hypothalamus which is:

“….responsible for regulating your hunger, thirst, response to pain, levels of pleasure, sexual satisfaction, anger and aggressive behaviour, and more. It also regulates the functioning of the autonomic nervous system, which in turn means it regulates things like pulse, blood pressure, breathing, and arousal in response to emotional circumstances.” (wiki)

They are also often referred to as our primitive – or innate responses – we have them from birth.
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These responses are hard wired and include what are known as fight or flight – emergency responses.

It is these parts which hold these powerful emotional responses that are affected or exposed.

The parts surrounding this are the areas of the brain that develop as the brain develops and that manage these primitive responses. These areas are also apparently affected – but they are areas that can effectively repair.

This would explain why many children – whose brains are still growing rapidly appear to improve more quickly after a period of extreme responses.
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So what can we do?
Be inquisitive – what is it that bothers us the most?
Manage the symptoms
Seek help
Find ways of supporting the persons development of the brain – to “manage” emotions