

Insight into well-being of patients with Narcolepsy transitioning from Paediatric to Adult service

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January 2017

Aim for 2016

- Set up the framework for the development of a new Narcolepsy service at St. James's Hospital Dublin.
- Transfer/Transition of patients over time from Temple St. Children's Hospital (50 in total).
- Most had developed narcolepsy following H1N1 vaccine in 2009-2010 (8/9).

Transition- background

- Over the winter of 2009-2010, the Health Services Executive in Ireland provided H1N1 vaccination to the Irish population in a phased manner. Pandemrix vaccine uptake was 38% in children 5- 19 years, with almost a million of total population receiving the vaccine. Nearly 90 patients (majority children and adolescents) have been diagnosed with Narcolepsy post H1N1 vaccination in Ireland since 2010. Some of the younger patients are ready to transition from paediatric to adult services.
- Transitioning is the planned move of a patient's care from paediatric care to an adult health care provider. It is a step necessary to achieve the best outcomes in areas of health, independence and adulthood.
- By the final phase, the young person should have a considerable degree of autonomy over their care.

Transition

- Transition should be a planned process, delivered in phases. The concept of transition should be introduced in early adolescence, with the young person becoming aware of their own health and care needs, and the full implications of their medical condition. Progression through phases should be based on the young persons' understanding and their confidence in their own autonomy.

Six key areas should be addressed in all phases of transition and these are:

- Self advocacy
- Independent health care behaviour
- Sexual health
- Psycho social support
- Educational and vocational planning
- Health and lifestyle

What did we do?

- Attended narcolepsy clinics in Temple St. Children's Hospital- met all patients prior to transition.
- Transition meeting in adult service in conjunction with the paediatric hospital team and invited families to attend.
- Contacted all patients directly, prior to their appointment to offer information regarding location and questionnaires to be completed prior to attending clinic.
- General clinic questionnaire and FOSQ and SF-36 aiming to get an insight into their well-being at the time of transition.

Questionnaire

Narcolepsy Review for Clinic SJH-

*Please complete this form before your clinic visit and bring it with you to your appointment

Name: _____ DOB: _____ Date completed: _____

Medications	Doses	Times	Side-effects

Sleep	Bed Time/Duration
Weekdays	
Weekends	

Naps	Time/Duration
Weekdays	
Weekends	

	Comments
Is sleep broken/unbroken	
Sleep Walk/talk	
Sleep Paralysis	
Vivid dreams /Nightmares	
Night time eating	
Snoring	
Restless Legs	

Cataplexy	Comment
Weak/Falls	
Facial appearance (avoiding laughing to prevent cataplexy)	

Work/ School	Comments re progress

Activity/Sports/Clubs	Frequency

Mood/Behaviour	Comments

Diet	Comments
Food intake	
Weight Gain/Loss	
Smoking cigarettes/weed	
Average alcohol per week	

Are you currently driving?	Yes/No
Any other issues to be discussed at Clinic:	Yes/No
For example, Personal relationships; Alcohol; Smoking:	Yes/No

Epworth Sleepiness Scale (Johns 1990-1997)

This scale will demonstrate how likely you are to doze off/fall asleep in certain situations, in contrast to feeling just tired. This refers to your usual daily life in recent times. Even if you haven't done the following recently try to work out how they would have affected you.

Use the following scale to choose the most appropriate number for each situation:

- 0 = would never doze
- 1 = slight chance of dozing
- 2 = moderate chance of dozing
- 3 = high chance of dozing

Sitting and reading	
Watching TV	
Sitting, inactive in a public place (e.g. a theatre or a meeting)	
As a passenger in a car for an hour without a break	
Lying down to rest in the afternoon when circumstances permit	
Sitting and talking to someone	
Sitting quietly after a lunch without alcohol	
In a car driving, while stopped for a few minutes in the traffic	

What do we know?

- 18 patients have transitioned to adult services to date.
- Small sample of the overall group (n=9) transitioning and gives an insight into their overall well-being at time of transition.
- Will help direct the future management and development of this new service.
- Data obtained from questionnaires & medical charts with the consent of each patient.
- Work in progress- ongoing in 2017.

Demographics

9 Transitioned Patients

Average age 18

3 Female and 6 male patients

8 Type 1 Narcolepsy & 1 Type 2

Mean BMI= 28

Mean ESS= 14

5 in 2nd level education, 3 in third and 1 waiting to commence a course



Ongoing Symptoms

Symptoms	Number of patients
Daytime Sleepiness	9
Cataplexy	8
Disturbed Nocturnal Sleep	7
Sleep Paralysis	3
Hypnagogic Hallucinations	2
Nightmares	3

What did we find-medication

Medication	No. of patients on each medication
Methylphenidate	5
Methyphenidate SR	4
Modafinil	2
Venlafaxine	4
Sodium Oxybate	2

- 1 patient is on 4 medications
- 2 patients on 3 medications
- 2 patients on 2 medications
- 1 on no medications.

What did we find?

- Lifestyle: 4 patients occasionally have alcohol and a fifth smokes.
- 5 involved in sporting activities.
- Only one patient drives, mild narcolepsy, no medications.
- Two patients also diagnosed with OSA & commenced on CPAP, with a third pending.



FOSQ

- Just less than **50%** said they have a degree of difficulty maintaining a phone conversation due to being sleepy/ tired.
- Around **66%** have difficulty with visiting family/friends both in their *own home* and in family/friends homes.
- More than **50%** felt their relationship with family/friends/work colleagues had been affected because of being sleepy or tired.
- **5** felt they had difficulty being active in the morning, this increased to **8** of the patients in the afternoon/evening.
- **7** patients felt they had difficulty keeping pace with others their own age.

FOSQ

Activity Levels	No of Patients
High	1
Medium	5
Low	1
Very low	2

SF-36

- General level of health was viewed as very good/good by most, one patient perceived his health as excellent and one as fair.
- The majority felt their general health was the same as one year ago, one third felt it was some degree worse than the previous year.
- Majority of patients had felt 'full of life' at some stage in previous 4 weeks.
- Two thirds had felt so down in the dumps in the last 4 weeks that nothing could cheer them up.
- All except one felt calm and peaceful at some stage in the previous 4 weeks.

SF-36

- The majority felt tired all or most of the time.
- Four patients felt worn out most of the time.
- Only two patients reported having a lot of energy most of the time.
- Over half said they had been a happy person a good bit of the time.
- Only two hadn't felt downhearted or low.
- All reported that their physical health/emotional problems had affected their social activities.
- Two felt they seemed to be ill more easily than other people.

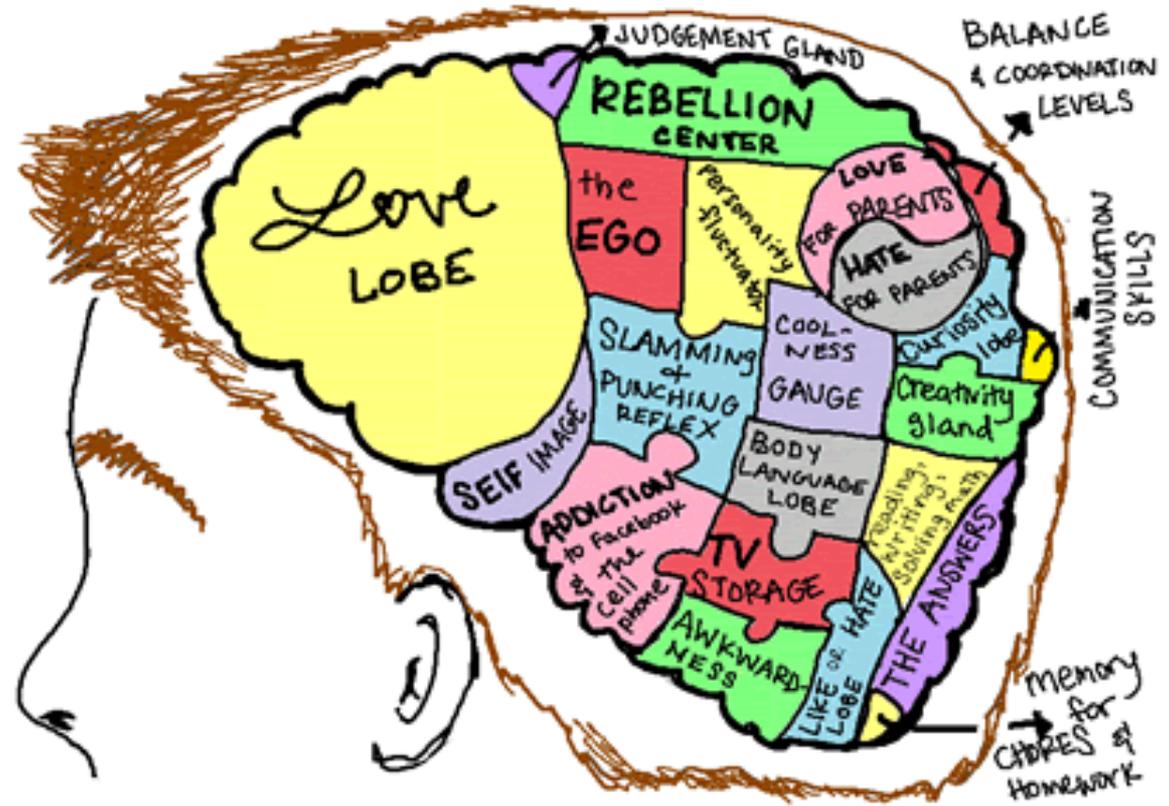
SF-36

- Four felt they were as healthy as anyone they knew.
- Only three patients rated their health as excellent.
- Four patients didn't expect their health to get worse, one felt this statement was false and the remainder didn't know.

Conclusion

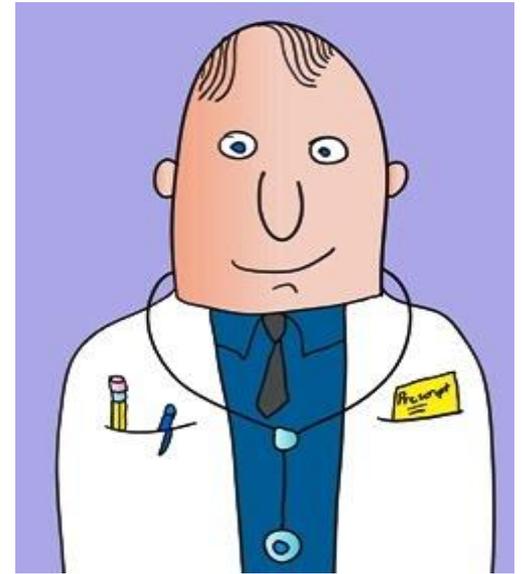
- Small sample, starting point.
- Despite difficulties group in general were doing reasonably both educationally and socially.
- Continuing to collect information in 2017.
- Inform service development and help to focus on areas of greatest need.
- Information will support the development of the MDT for the Narcolepsy service.

THE AVERAGE TEENAGE BRAIN



Acknowledgements

- Dr. Catherine Crowe
- Dr. Colin Doherty- St. James's Hospital
- Siobhán O'Malley (CNS) & Dr Bryan Lynch- Temple St. Children's Hospital, Dublin
- Narcolepsy group St. James's Hospital
- Mater Private Hospital, Dublin.



Questions

