

Bare Bones of RLS Handout developed by Kate Condon –October 2022

After the recent survey by the European Federation of Neurological Associations (EFNA) October 3rd 2022— highlighting the more-than-disappointing results on skills of medical personnel.

SURVEY RESULTS: Assessing diagnosis and care pathways of people living with neurological disorders

This 'handout' or very similar, should be the basic 'Bare Bones' of RLS education for medical students , GP trainees, junior neurologists, RLS patients , caregivers , interested relatives and general public.

EVERYONE SHOULD KNOW WHAT IS EXPECTED FROM THE FIRST CONSULTATION WITH MEDICAL PERSONNEL. It will not complete the whole personal plan but (i) they feel listened to and (ii) they can see that they are at least on the way to caring and compassionate help with their Restless Legs Syndrome

Below is the 1-10 points (or very similar) required in the urgently needed 'BARE BONES' of RESTLESS LEGS SYNDROME 'handout', which should be (written formally by the Association of British Neurologists , ABN) and given to the patient at the 1st consultation with a doctor, usually the GP

1. Empathy and compassionate attitude, very focused history taking
2. Consideration of differential diagnostic red flags, separate from or possibly associated with RLS
3. Assess degree of severity- mild, moderate or severe
4. Moderate/severe subjects, arrange for a blood test, (general parameters, fbc, CRP, blood glucose TFTs) plus an 'iron' panel. Fasting iron, TIBC or transferrin, ferritin and TSAT as a percentage

5. Suggest IRLSSG Rating scale to all moderate /severe subjects for 4-6 weeks

6. Give all mild/mod/severe subjects a handout written by ABN? with all of the above points plus signposting to RLS-UK and all other useful latest research. They can take it home, stick it on their fridge door and read and study it over the coming weeks, probably when they are stamping around at 2am, unable to sleep.

7. Organise follow up appointment for 4-6 weeks for moderate/severe subjects to check rating scale results, discuss blood test results and discuss treatment options.

8. Discuss treatment options. For moderate/severe, most should have intravenous iron. Dispel 'fallacious fear of raised ferritin' (not the sensible scientific care in avoiding iron overload).

9. Mild subjects, receive the handout and should attend in future if the condition worsens (+ possible blood test etc. if ? anemic or other diagnoses)

10. Alternative treatment options - intravenous iron, alpha 2 delta ligands, opioids, methadone, buprenorphine etc. and only if absolutely necessary and after logical, careful treatments and failure of them, and probable referral to secondary care or incredibly careful monitoring of the possibility of development of augmentation).....way down the order, Dopamine agonists.

*Any medications that worsen RLS, like anti-depressants and sedating anti-histamines should be reviewed and suitable alternatives considered.

Repeat intravenous ferric carboxymaltose case report

<https://www.karger.com/Article/FullText/518911#top>

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