



# Greg

## LIVING WITH PRIMARY ADRENAL INSUFFICIENCY

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Living without Adrenals -  
No Flight, No Fight!

In the early 90s, whilst working on a building site during the college holidays, a back injury resulted in a visit to A&E at a busy London hospital. An observant doctor noted unusual compression of the vertebrae and suggested follow up investigations. On return to Dublin and after various tests I was diagnosed with Cushing’s Disease – a pituitary adenoma causing excessive ACTH, in turn causing excess cortisol. All the tell-tale symptoms were evident – moon face, purple striations on trunk, thin skin. Some months later the adenoma was surgically removed and this was followed 6 months later with a course of radiotherapy to the pituitary fossa. Unfortunately the excess cortisol levels remained. In the short term this was suppressed with medication but ultimately it was necessary to remove both adrenal glands. In effect through surgical intervention I ended up in the same situation as someone with Addison’s Disease, the under production of cortisol, called Primary

Adrenal Insufficiency (AI) due to faulty adrenal glands. So in my early 20s I found myself, not with an illness or a disease, but with a condition requiring lifelong daily medication to survive.

In Ireland, indeed worldwide, this is not a common condition, and certainly not one that is deemed worthy of inclusion under the Long Term Illness scheme. In contrast, when I was working in the UK and informed my GP there of my condition I was immediately given a steroid dependent card to carry and all my medication was free. One consolation is that that standard steroid replacement therapy in whatever form (dexamethasone, hydrocortisone, prednisolone and fludrocortisone) is relatively cheap – nevertheless anything that you require for life adds up!

Despite my steroid dependency I am able to enjoy a good lifestyle but I always have to be aware of risks – a simple cut on my shin will take much longer to heal, gastro-intestinal upset prevents absorption of oral medications, fludrocortisone must be stored in a fridge. The

greatest concern is reduced bone density - this requires regular monitoring and over the years several different medications have been taken.

As I am now in my 50s I would like to be able to share my experiences with others who may be diagnosed with Cushing's, and also to hear and learn from others about treatment regimens and their experiences. I am particularly interested in new developments with modified release corticosteroids which mimic the body's natural diurnal production of steroids. I would like to see the establishment of a national register of people with Adrenal Insufficiency and a more inclusive approach by the HSE for those requiring lifelong medication to live.