

Authors

Lisa Shepherd¹, Aldons Chua², Cathy Thompson³, Amy Shingler⁴, Philippa Sharman³, Emma Cooper⁴, John Wass⁵, Antonia Brooke⁶

1. University Hospitals Birmingham NHS Foundation Trust and University of Birmingham, UK. 2. City St Georges University of London, UK. 3. Addison's Disease Self-Help Group, UK. 4. Pituitary Foundation, UK. 5. Department of Endocrinology, Churchill Hospital, Oxford, UK. 6. MacLeod Diabetes & Endocrine Centre, Royal Devon University Healthcare NHS Trust, Exeter, UK.



Background

Patients frequently report to UK Patient Support Groups (PSGs), that they experience difficulties obtaining essential endocrine medications, particularly when requesting extended prescription supplies, causing anxiety, stress and risking inadequate supplies for adrenal insufficiency patients following Sick Day Rules.

A reliable medication supply, including during illness and travel, is emphasized in NICE Guidelines on the Identification and Management of Adrenal Insufficiency, including the need to tailor treatment to individual patients and involve them in decision making. A systematic review comparing 3-month versus 28-day prescription durations found that longer supplies can be cost effective.

Objective

To explore UK patient experiences of accessing essential glucocorticoid medication for adrenal insufficiency.

Method

An on line-survey was designed by clinical advisors and staff members of the Addison's Disease Self-Help Group (ADSHG) and the Pituitary Foundation (PF). The four week survey was shared via PSG social media and member communications. Eligible respondents were UK residents aged 18 years or over, on essential medications including glucocorticoids, desmopressin, levothyroxine, testosterone & oestrogen.



Questions focused on:

- Prescription frequency for essential endocrine medications
- The outcome of approaches to GPs for an extended prescription
- Patient comments, insights and concerns

Results & Key Findings

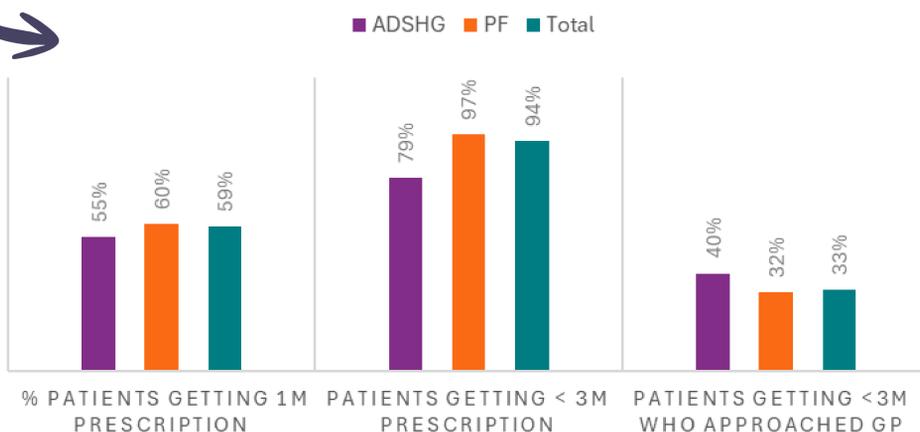
A total of 1724 patients responded (1399 PF, 325 ADSHG).

Most respondents received less than a 3-month supply (97% PF, 78.8% ADSHG), with over half receiving only a 28-day supply (60% PF, 55% ADSHG).

Among those receiving shorter prescriptions, 33% had previously asked their GP for a longer duration. Reasons for refusal included concerns about medicine wastage, stockpiling, supply chain issues, patient safety, local policy or no reason given.

Additional challenges included long

PRESCRIPTION LENGTH OF VITAL STEROID MEDS



processing times (5-7 days), difficulty sourcing hydrocortisone succinate, delayed hospital-GP communication, and low patient awareness of the possibility of longer prescription duration.

My GP and GP pharmacist will not prescribe me more than 1 month hydrocortisone or extra supply for sick day rules and if I have to take extra they tell me I'm overusing steroids

I feel drained and ready to give up on the subject!

I was not allowed to speak to a GP at my surgery. The receptionist finally had the pharmacist call who told me it's their policy to only issue 1-months supply

Conclusion

Despite national guidance, many endocrine patients continue to face significant barriers in accessing sufficient medication supplies. Survey responses underscore the urgency of action and the strength of the patient voice.

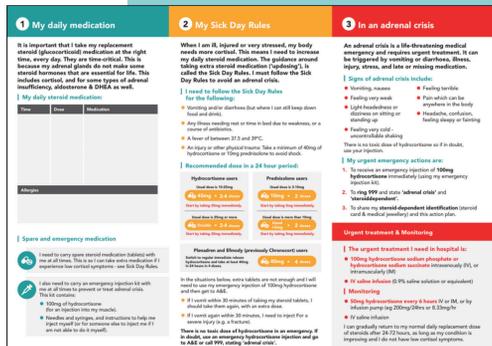
What can you do?

- Ensure your patients have access to a 3-month prescription for their essential glucocorticoid and vital endocrine medication and prompt this on clinic letter outcomes.
- Download & Share Adrenal Insufficiency Action Plan for adrenal insufficiency patients, including Addison's disease, and GP letter templates, to support 3-month prescriptions with their GP & pharmacy.

What we are doing?

- The project working group is in active discussions with the NHS England National Clinical Director for Prescribing to increase standard prescription durations to at least 56 days and ensure timely access to 'sick day' medication supplies.

- ADSHG & PF will continue to drive progress through professional education and awareness campaigns.



References:

1. NICE Guidelines for Identification & Management of Adrenal Insufficiency: www.nice.org.uk/guidance/NG243
2. NICE Guideline: Medicines Optimisation: the safe and effective use of medicines to enable the best possible outcomes: www.nice.org.uk/guidance/ng5
3. Clinical effectiveness and cost effectiveness of issuing longer versus shorter duration (3-month vs 28-day prescriptions) in patients with chronic conditions; systematic review and economic modelling - PubMed. www.ncbi.nlm.nih.gov/29268843

