

**An open letter from the Addison's Disease Self-Help Group (ADSHG UK), Alex TLC, and CAH Support Group Endocrinologists and Medical Authorities in Brazil**

To all those supporting people with Adrenal Insufficiency in Brazil. We, the undersigned, offer our best wishes at this difficult time. During this unprecedented time, we have been working closely with international adrenal insufficiency support groups, to standardise and maximise the care that people with adrenal insufficiency receive.

In response to a request from Associação Brasileira Addisoniana, who have reached out to International Addison's groups, we would strongly endorse the principle of providing sufficient steroid medication, both oral and parenteral, to allow increased personal health management and potentially decrease the burden on the health care system from patients experiencing adrenal crises during the pandemic.

This would include allowing patients to have sufficient supplies of oral hydrocortisone to take a much larger dose if they contract COVID19 or become ill with an unrelated illness. The current recommendation is to increase to hydrocortisone 20mg every 6 hours, or 80mg in a day. This means patients need an extra 8 weeks supply of their regular medication to be safe.

We also ask that you give careful consideration to providing emergency injection kits as standard to prevent hospital admissions and deaths in this community, especially during the time of higher risks of complications due to COVID-19. These include 2 or 3 vials of hydrocortisone 100mg for IM use, along with 23g needles and 2ml syringes. This small amount of medication costs around \$2.00 or £1.50 and can save the life of a person with adrenal insufficiency if they are vomiting or otherwise seriously ill. We also ask that patients are educated on how to use it.

82% of members of the Addison's Disease Self Help group in the UK have been provided with emergency hydrocortisone injection kits that they can self-administer when experiencing symptoms of adrenal crisis. In times of social distancing, they learn how to inject with the help of our online videos and demonstrations from their endocrine team.

An adrenal crisis can develop quickly and waiting for emergency medical attention, an emergency hydrocortisone injection, or infusion can mean the difference between life and death.

**Contents of emergency kits should contain:**

- Emergency vials of hydrocortisone. This can be hydrocortisone sodium succinate (Solu-Cortef, Act-O-Vial), a powder that requires reconstitution or Hydrocortisone sodium phosphate (a liquid preparation).

- Water for injection for Solu-cortef injections.
- Syringes (2ml) and needles suitable for intramuscular injection.
- Printed instructions on how to administer injection.
- Vial snaps or other protection for opening glass vials.

We recommend that all patients should be equipped with a steroid emergency card and medical alert identification to inform health personnel of the need for increased glucocorticoid doses to avert or treat adrenal crisis and the need of immediate parenteral steroid treatment in the event of an emergency. (Ungraded best practice statement)

**Further information, guidance and recommendations are provided below, written by our own medical colleagues and valued partners.**

Arlt, W., Baldeweg, S., Pearce, S., & Simpson, H. (2020). Endocrinology in the time of COVID-19: Management of adrenal insufficiency, *European Journal of Endocrinology*, , EJE-20-0361. Retrieved May 6, 2020, from <https://ije.bioscientifica.com/view/journals/eje/aop/eje-20-0361/eje-20-0361.xml>

#### **How to avoid precipitating an acute adrenal crisis**

<https://www.addisonsdisease.org.uk/Handlers/Download.ashx?IDMF=e5cb094e-f146-43db-8c34-f387485fb4a9>

#### **Guidelines for the management of glucocorticoids during the peri-operative period for patients with adrenal insufficiency**

Guidelines from the Association of Anaesthetists, the Royal College of Physicians and the Society for Endocrinology UK. T. Woodcock, P. Barker, S. Daniel, S. Fletcher, J. A. H. Wass, J. W. Tomlinson, U. Misra, M. Dattani, W. Arlt A. Vercueil <https://onlinelibrary.wiley.com/doi/full/10.1111/anae.14963>

#### **The following guidance is issued to ADSHG members:**

<https://www.addisonsdisease.org.uk/emergency>

We are available to support the development of any required guidelines and approaches to help make this possible.

Thank you for your consideration.

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**US Endocrine Nurses Society (ENS)**

**Federation of International Nurses in Endocrinology (FINE)**