

Adrenal insufficiency: identification and management

Information for the public

Published: 28 August 2024

www.nice.org.uk

Adrenal insufficiency: the care you should expect

Adrenal insufficiency is when the adrenal glands do not make enough glucocorticoid hormones. Primary adrenal insufficiency is caused by disease in the adrenal glands themselves (Addison's disease is the most common cause in adults, and congenital adrenal hyperplasia is the most common cause in children). Secondary or tertiary adrenal insufficiency can be caused by pituitary disease, tumours in the pituitary or hypothalamus, or by taking glucocorticoid medication for a long time. People with adrenal insufficiency can live full and active lives if they receive consistently good information and care, but it can still have a big impact on their everyday life. If adrenal insufficiency is not treated, it can lead to a sudden worsening of symptoms called an adrenal crisis. An adrenal crisis is a medical emergency and can be fatal if left untreated.

We want this guideline to make a difference to people with adrenal insufficiency by making sure:

- They know how to get medical alert jewellery and cards to carry ([NHS Steroid Emergency Card](#) for adults or [British Society of Paediatric Endocrinology and Diabetes \(BSPED\) Emergency Steroid Card](#) for children and young people) so health professionals will know about their condition quickly.
- They know when to take extra medication (for example, when unwell, having surgery, or during very stressful times such as a bereavement, exam, wedding or divorce).
- They are given emergency management kits (containing hydrocortisone for intramuscular injection that can be given by anyone when adrenal crisis is suspected) and training on how to use them.
- They receive pre-pregnancy counselling and antenatal care from a team with knowledge of managing adrenal insufficiency during pregnancy.
- Health professionals know about the symptoms of an adrenal crisis so that it is treated as quickly as possible.
- When people need to stop taking glucocorticoids for other conditions, this is done slowly over time to help prevent adrenal insufficiency.

Making decisions together

Decisions about treatment and care are best when they are made together. Your healthcare professionals should give you clear information, talk with you about your options and listen carefully to your views and concerns.

To help you make decisions, think about:

- What matters most to you – what do you want to get out of any treatment?
- What are you most worried about – are there risks or downsides to the treatment that worry you more than others?
- How will the treatment affect your day-to-day life?
- What happens if you don't want to have treatment?

If you need more support to understand the information you are given, tell your healthcare professional.

Read more about [making decisions about your care](#).

Where can I find out more?

The [NHS website](#) has more information about primary adrenal insufficiency (also known as Addison's disease).

The organisations below can give you more advice and support.

- [Addison's Disease Self-Help Group \(ADSHG\)](#)
- [Living with CAH](#)
- [The Pituitary Foundation](#), 0117 370 1320 (general information helpline) or 0117 370 1317 (endocrine nurse helpline).

To share an experience of care you have received, contact your local [Healthwatch](#).

NICE is not responsible for the content of these websites.

We wrote this guideline with people who have been affected by adrenal insufficiency and staff who treat and support them. All the decisions are based on the best research available.

ISBN: 978-1-4731-6447-5