

1           **NATIONAL INSTITUTE FOR HEALTH AND CARE**  
2           **EXCELLENCE**

3                           **Guideline scope**

4           **Adrenal insufficiency: acute and long-term**  
5           **management**

6           NHS England has asked NICE to develop a guideline on acute and long-term  
7           management of hypoadrenalism (adrenal insufficiency).

8           The guideline will be developed using the methods and processes outlined in  
9           [developing NICE guidelines: the manual](#).

10       **1           Why the guideline is needed**

11       Adrenal insufficiency is the inadequate production of corticosteroid hormones  
12       by the adrenal glands. Adrenal insufficiency may be:

- 13       • primary, that is, because of disease in the adrenal glands themselves (the  
14       autoimmune condition, Addison's disease, is the commonest)
- 15       • secondary, that is, caused by inadequate adrenocorticotrophic hormone  
16       production by the pituitary gland (often because of treatment for a pituitary  
17       adenoma)
- 18       • tertiary, that is, caused by inadequate corticotrophin releasing hormone  
19       production by the hypothalamus (often because of treatment for tumours in  
20       the hypothalamus or adjoining structures, or because of administration of  
21       glucocorticoids for more than 4 weeks).

22       Adrenal insufficiency may have a considerable effect on daily living, and may  
23       lead to adrenal crisis if not identified and treated. Common causes of adrenal  
24       crisis in people with adrenal insufficiency are gastrointestinal illness (23%),  
25       other infections (25%), surgery (10%) and physiological stress (9%). Adrenal  
26       crisis is a medical emergency and can be fatal.

## 1 **Current practice**

2 The mainstay of adrenal insufficiency management is replacement with  
3 glucocorticoid and mineralocorticoid preparations. These medicines are  
4 usually given orally, to maintain a good quality life and to prevent adrenal  
5 crisis. Treatment for adrenal crisis typically includes prompt administration of  
6 glucocorticoids (100 mg hydrocortisone intravenously or intramuscularly) and  
7 crystalloid fluid.

8 Care is variable in the UK and small numbers of people die each year from  
9 adrenal crisis. Although deaths are rare and avoidable, awareness needs to  
10 be raised about the importance of glucocorticoid replacement in people with  
11 adrenal insufficiency who are at risk of adrenal crisis. There is an [NHS Steroid](#)  
12 [Emergency Card](#) for people at risk to carry to help ensure prompt appropriate  
13 treatment if they have an adrenal crisis.

14 Better recognition of people at risk of adrenal insufficiency, and awareness of  
15 the acute- and long-term management of adrenal insufficiency, would improve  
16 patient care and quality of life, and reduce associated complications. This  
17 guideline aims to improve the management of adrenal insufficiency and the  
18 quality of life of people with adrenal insufficiency.

## 19 **2 Who the guideline is for**

20 This guideline is for:

- 21 • health and social care practitioners providing NHS-commissioned services,  
22 including those working in dental services, school health services and  
23 prehospital care
- 24 • commissioners of health and social care services
- 25 • people using services, their families and carers, and the public.

26 It may also be relevant for non-NHS healthcare providers of dental services.

27 NICE guidelines cover health and care in England. Decisions on how they  
28 apply in other UK countries are made by ministers in the [Welsh Government](#),  
29 [Scottish Government](#), and [Northern Ireland Executive](#).

## 1 **Equality considerations**

2 NICE has carried out [an equality impact assessment](#) during scoping. The  
3 assessment:

- 4 • lists equality issues identified, and how they have been addressed
- 5 • explains why any groups are excluded from the scope.

6 The guideline will look at inequalities relating to age, disability and people who  
7 are homeless.

## 8 **3 What the guideline will cover**

### 9 **3.1 Who is the focus?**

#### 10 **Groups that will be covered**

11 Babies, children, young people and adults with suspected and diagnosed  
12 adrenal insufficiency.

13 Specific consideration will be given to babies and children.

### 14 **3.2 Settings**

#### 15 **Settings that will be covered**

16 All settings in which NHS-commissioned care is provided.

### 17 **3.3 Activities, services or aspects of care**

#### 18 **Key areas that will be covered**

19 We will look at evidence in the areas listed below when developing the  
20 guideline, but it may not be possible to make recommendations in all these  
21 areas.

- 22 1 Information and support for people with suspected and diagnosed  
23 adrenal insufficiency (and their families and carers).
- 24 2 Initial identification of people with suspected adrenal insufficiency who  
25 may benefit from referral for specialist investigation and care.

- 1 3 Managing adrenal insufficiency:
- 2 – adrenal crisis
- 3     ⇒ identification of adrenal crisis
- 4     ⇒ emergency management
- 5 – routine (non-emergency) management
- 6     ⇒ pharmacological treatment of primary adrenal insufficiency, and
- 7     secondary and tertiary adrenal insufficiency
- 8 – preventing adrenal crisis during periods of physiological stress:
- 9     ⇒ minor illnesses (for example, colds) and major illnesses (for
- 10     example, severe infection, cardiac events)
- 11     ⇒ planned and emergency invasive procedures
- 12     ⇒ pregnancy and intrapartum care
- 13 – preventing adrenal crisis during periods of psychological stress.
- 14 4 Ongoing care and monitoring, that is, the frequency and content of
- 15 monitoring of adrenal insufficiency.

16 Note that guideline recommendations for medicines will normally fall within

17 licensed indications. Exceptionally, and only if clearly supported by evidence,

18 use outside a licensed indication may be recommended. The guideline will

19 assume that prescribers will use a medicine's summary of product

20 characteristics to inform decisions made with individual patients.

### 21 **Areas that will not be covered**

- 22 1 Adrenal fatigue.
- 23 2 Diagnosing adrenal insufficiency.
- 24 3 Diagnosing, managing and monitoring the underlying medical conditions
- 25 that causes adrenal insufficiency.
- 26 4 Weaning from corticosteroids that have been prescribed for reasons
- 27 other than adrenal insufficiency.

## 1 **Related NICE guidance**

### 2 **Published**

- 3 • [Myalgic encephalomyelitis \(or encephalopathy\)/Chronic Fatigue Syndrome: diagnosis and management](#) (2021) NICE guideline NG206
- 4
- 5 • [Type 1 diabetes in adults: diagnosis and management](#) (2021) NICE
- 6 guideline NG17
- 7 • [Diabetes \(type 1 and type 2\) in children and young people: diagnosis and](#)
- 8 [management](#) (2020) NICE guideline NG18
- 9 • [Intrapartum care for women with existing medical conditions or obstetric](#)
- 10 [complications and their babies](#) (2019) NICE guideline NG121
- 11 • [Active B12 assay for diagnosing vitamin B12 deficiency](#) (2015) Medtech
- 12 innovation briefing MIB40
- 13 • [Lower urinary tract symptoms in men: management](#) (2015) NICE guideline
- 14 CG97
- 15 • [Endoscopic transsphenoidal pituitary adenoma resection](#), (2003).
- 16 Interventional procedures guidance IPG32

### 17 **NICE guidance about the experience of people using NHS services**

18 NICE has produced the following guidance on the experience of people using  
19 the NHS. This guideline will not include additional recommendations on these  
20 topics unless there are specific issues related to adrenal insufficiency:

- 21 • [Shared decision making](#) (2021) NICE guideline NG197
- 22 • [Babies, children and young people's experience of healthcare](#) (2021) NICE
- 23 guideline NG204
- 24 • [Medicines optimisation](#) (2015) NICE guideline NG5
- 25 • [Patient experience in adult NHS services](#) (2012) NICE guideline CG138
- 26 • [Service user experience in adult mental health](#) (2011) NICE guideline
- 27 CG136
- 28 • [Medicines adherence](#) (2009) NICE guideline CG76

### 1 **3.4 Economic aspects**

2 We will take economic aspects into account when making recommendations.  
3 We will develop an economic plan that states for each review question (or key  
4 area in the scope) whether economic considerations are relevant. If so, we will  
5 state whether this is an area that should be prioritised for economic modelling  
6 and analysis. We will review the economic evidence and carry out economic  
7 analyses, using the NHS and personal social services (PSS) perspective, as  
8 appropriate.

### 9 **3.5 Key issues and draft questions**

10 1 Information and support:

11 1.1 What information and support do people with suspected or  
12 diagnosed adrenal insufficiency (and their families and carers) need  
13 to routinely manage their health (including how to ensure an  
14 adequate supply of medicines, advice on what to do in certain  
15 situations such as when exercising, traveling, working non-standard  
16 hours or taking part in religious observances such as fasting)?

17 1.2 What information and support do people diagnosed with adrenal  
18 insufficiency need for the prevention and emergency care of an  
19 adrenal crisis?

20 2 Initial identification for referral of people with suspected adrenal  
21 insufficiency:

22 2.1 When should adrenal insufficiency be suspected (for example, based  
23 on risk factors or symptoms)?

24 2.2 What initial investigations should be done by the non-specialist for  
25 people with suspected adrenal insufficiency?

26 2.3 When should people with suspected adrenal insufficiency be referred  
27 to specialists for further investigation?

28 3 Managing adrenal insufficiency:

29 3.1 What is the clinical and cost effectiveness of pharmacological  
30 treatments for the routine management of primary adrenal  
31 insufficiency?

- 1 3.2 What is the clinical and cost effectiveness of pharmacological  
2 treatments for the routine management of secondary and tertiary  
3 adrenal insufficiency?
- 4 3.3 When should adrenal crisis be suspected?
- 5 3.4 What is the clinical and cost effectiveness of pharmacological  
6 treatments for the emergency management of adrenal crisis?
- 7 3.5 What is the clinical and cost effectiveness of pharmacological  
8 treatments for managing periods of physiological stress in people  
9 with adrenal insufficiency including:
- 10 a) planned and emergency invasive procedures
- 11 b) pregnancy and intrapartum care
- 12 c) intercurrent illness and periods of physiological stress including  
13 minor (for example, colds) and major illnesses (for example, severe  
14 infection, cardiac events)?
- 15 3.6 What is the clinical and cost effectiveness of pharmacological  
16 treatments for managing periods of psychological stress in people  
17 with adrenal insufficiency?
- 18 3.7 What is the clinical and cost effectiveness of non-pharmacological  
19 strategies to prevent adrenal crisis during periods of intercurrent  
20 illness and periods of physiological stress?
- 21 3.8 What is the clinical and cost effectiveness of non-pharmacological  
22 strategies to prevent adrenal crisis during periods of psychological  
23 stress?
- 24 4 Ongoing care and monitoring
- 25 4.1 What ongoing care and monitoring should be offered to people with  
26 adrenal insufficiency?
- 27 4.2 What ongoing care and monitoring should be offered to people with  
28 adrenal insufficiency who are receiving end of life care?
- 29
- 30 The key issues and draft questions will be used to develop more detailed  
31 review questions, which guide the systematic review of the literature.

### 1 **3.6 Main outcomes**

2 The main outcomes that may be considered when searching for and  
3 assessing the evidence are:

- 4 1 mortality
- 5 2 health-related quality of life
- 6 3 complications of adrenal insufficiency
- 7 4 fatigue
- 8 5 adrenal crisis
- 9 6 complications of adrenal crisis
- 10 7 treatment-related adverse events.

## 11 **4 Further information**

This is the draft scope for consultation with registered stakeholders. The consultation dates are 01 February 2022 to 01 March 2022.

The guideline is expected to be published on 04 April 2024.

You can follow progress of the guideline at:

<https://www.nice.org.uk/guidance/indevelopment/gid-ng10237>

Our [website has information about how NICE guidelines](#) are developed.

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