

Study Title

Exploring factors associated with adrenal crisis: findings from a UK national survey of adults with adrenal insufficiency

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Adrenal Crisis: How Common Is It and What Affects the Risk?

Adrenal crisis is a serious and life-threatening emergency that can affect people living with adrenal insufficiency. It occurs when the body does not have enough cortisol, a hormone that plays a vital role in maintaining blood pressure, energy levels, and the body's response to illness or stress. In situations of increased physical and emotional stress, and low cortisol levels, people can rapidly become very unwell, experiencing symptoms such as severe weakness, vomiting, confusion, and dangerously low blood pressure. Without urgent treatment, an adrenal crisis can be fatal.

Although adrenal crisis is often preventable, it remains a significant concern. Each year, around 6–8% of people with adrenal insufficiency experience an adrenal crisis, and nearly 1 in 200 of those who experience an adrenal crisis may die from a potentially preventable episode. Immediate treatment with an injection of hydrocortisone is essential and can quickly reverse symptoms.

To better understand how often adrenal crises occur and what influences them, we conducted a UK-wide survey in 2024 involving 1,789 adults with adrenal insufficiency, recruited through patient support groups and 28 NHS endocrine centres. The study explored how people manage their condition in daily life, including medication use, "sick day rules" and stress dosing, and responses to adrenal crisis, as well as their experiences of education and support.

How common are adrenal crises?

Among **1,761 participants**, **561 people (32%)** reported at least one adrenal crisis in the past year, while **1,200 (68%)** reported none. Most people who experienced a crisis had one episode, although some reported multiple crises (Figure 1a).

Looking over a longer period, adrenal crisis was a common experience; **950 participants (54%)** had experienced at least one adrenal crisis since diagnosis (Figure 1b), and for **422 people (24%)**, the crisis was the event that led to their diagnosis (Figure 1c). These findings show that adrenal crisis is not rare; it is something many people with adrenal insufficiency will face at some point.

Figure 1a: Adrenal crises in past year

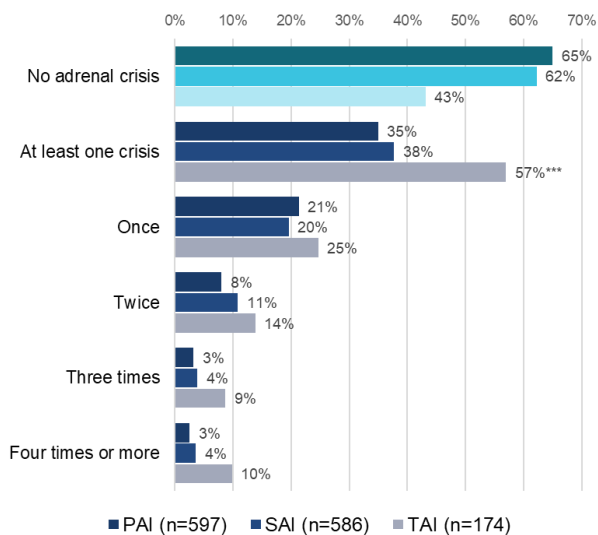


Figure 1b: Ever had an adrenal crisis?

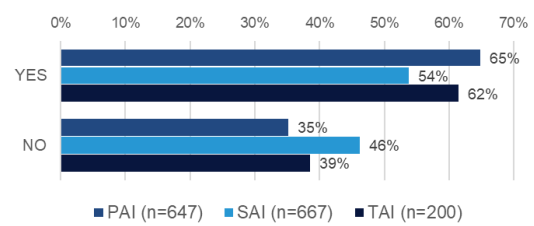


Figure 1c: Adrenal crises at diagnosis

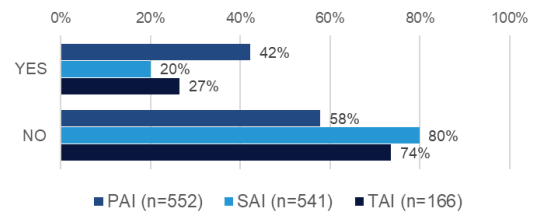


Figure 1 a – c: Prevalence of adrenal crises in adults with PAI (primary adrenal insufficiency), SAI (secondary adrenal insufficiency), and TAI (tertiary adrenal insufficiency).

Who is more likely to experience an adrenal crisis?

Clear patterns emerged across different groups in data collected from the **1,761 participants**. Younger adults were more affected, with 43% of those aged 26–35 reporting a crisis in the past year, compared with 24% of those aged over 66. Women were also more likely to experience a crisis than men (37% vs 22%).

Life circumstances also played a role. Among people receiving disability living allowance, 54% reported a crisis, compared with 30% of those working or studying and 24% of those who were retired. This suggests that people with greater health or social challenges may be at increased risk.

Clinical factors were equally important. People diagnosed within the past two years had the highest rates of crisis (43%), compared with 27% among those diagnosed more than 10 years ago, suggesting that symptom recognition and confidence in preventing a crisis improve over time. People with tertiary adrenal insufficiency, following treatment with high dose steroids, were particularly affected, with 45% reporting a crisis, compared with around 29–30% for other types (adrenal or pituitary-related causes).

Equipped with preventative tools

One of the most interesting findings was the relationship between being prepared and experiencing a crisis. Most people were well equipped; 1,547 participants (89%) reported having an emergency hydrocortisone injection kit, 1,425 (83%) carried an emergency steroid card (NHS or blue card), 1,591 (91%) had extra tablets for sick day dosing, 1,154 (67%) were wearing a medical alert ID, and 483 (28%) carried written instructions on how to manage an adrenal crisis. However, when considered in isolation, preventative tools were not associated with adrenal crisis rates.

However, some factors remained important even after taking everything into account. People who always carried their injection kit (819 people, 53%) were more likely to report a crisis, as were those who had someone else trained to give their injection (987 people, 57%). These findings likely reflect that people who are at higher risk, or who have experienced previous crises, are more vigilant and better prepared.

Medication habits and confidence

How people manage their medication also plays an important role. Those who experienced adrenal crises were more likely to report missing doses or not taking medication as prescribed. They were also more likely to feel both that hydrocortisone was essential and that they had concerns about taking it.

In contrast, people who took their medication more consistently were less likely to experience a crisis. This highlights the importance of routine, confidence, and understanding treatment, not just access to medication.

What happens during an adrenal crisis?

To better understand real-life experiences, we looked more closely at the **561 people** who had an adrenal crisis in the past year.

Although most people had an emergency injection kit, only 18% (101 people) were able to self-inject independently, 39% required assistance, most commonly from a family member or carer, while nearly half had to rely on emergency services (paramedics or A&E personnel) to give their hydrocortisone injection (Figure 2). This highlights a critical gap between having a kit and being able to use it in an emergency.

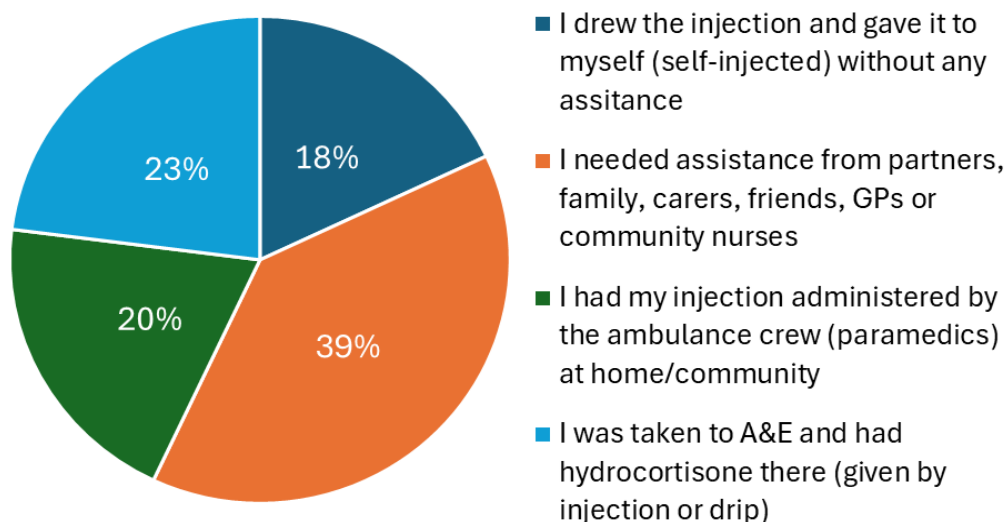
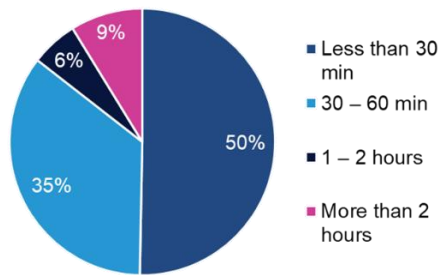


Figure 2: Who injected your hydrocortisone injection during your most recent adrenal crisis?

Among those treated by paramedics (N=91), around 80% received treatment within one hour, with about half treated within 30 minutes. In contrast, among those treated in A&E (N=108), only around half were treated within one hour, and nearly 30% waited more than two hours (Figure 3). This suggests that treatment is often faster in the community than in hospital, highlighting an important area for improvement.

Time to injection from calling an ambulance (n=159)



Time to injection after arriving in A&E (n=213)

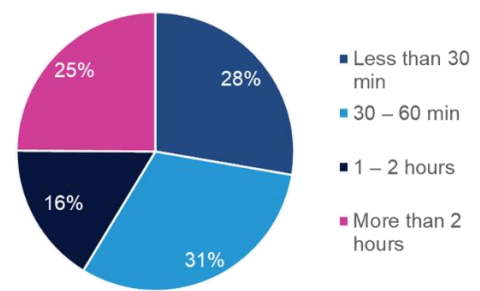


Figure 3: Time to emergency hydrocortisone injection during most recent adrenal crisis.

Does early treatment make a difference?

Overall, 66% (219 people) were admitted to hospital during their last adrenal crisis. However, among those who received an injection, 44% recovered without needing admission, suggesting that early treatment can make a difference. Patients who self-injected were **34% less likely to be admitted** compared with those receiving emergency care. Importantly, no other factors were linked to hospital admission, highlighting how critical **timely injection** is.

Among those who had one or more hospital admissions in the past year (including A&E attendance), 56% spent 1 - 3 days in hospital, 26% spent 4 - 7 days, and around 1 in 5 spent more than a week in total. These figures show that patients are spending a significant amount of time in hospital due to adrenal crises, many of which are potentially preventable. This represents a considerable burden, not only for patients and their families but also for the healthcare system.

What does this mean for patients?

These findings provide important insights and clearly show that earlier treatment, especially self-injection, is associated with better outcomes and fewer hospital admissions. Adrenal crisis risk and outcomes are shaped not only by medical factors, but also by confidence, preparation, and the ability to act quickly.

Even though most people have access to an emergency injection kit, many are unable to use it independently during a crisis. This reflects how physically and mentally overwhelming an adrenal crisis can be. Addressing this gap through better training, support, and faster emergency care, could reduce both the frequency and impact of adrenal crises.

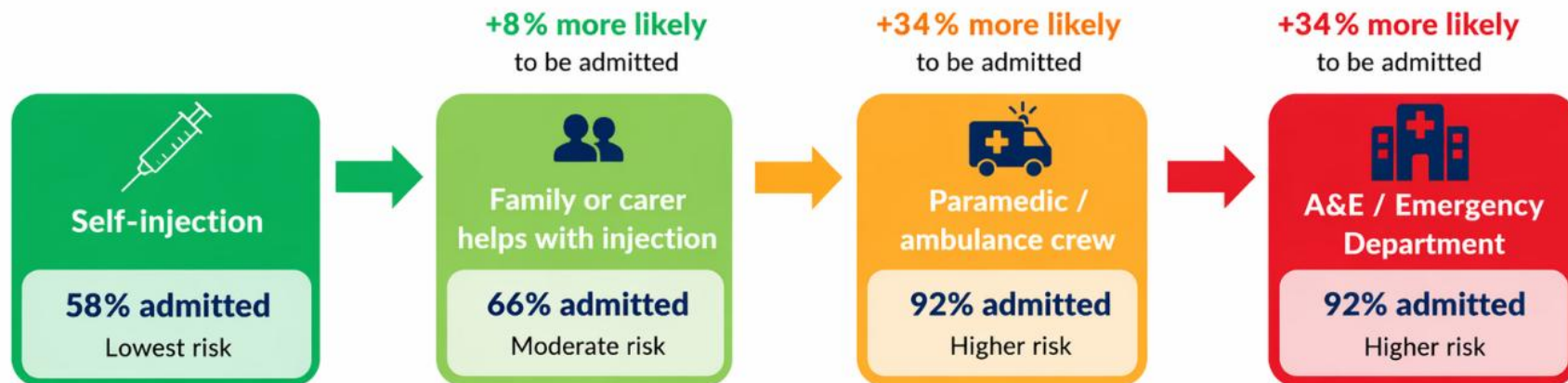
Next steps and the need for further research

While this study provides important insights into adrenal crisis risk and management, there are still important gaps. In particular, the survey captured limited information on how adrenal crises are managed within emergency care services, and did not fully map the patient journey from the onset of an impending crisis through to treatment and outcomes. To address this, a new UK-wide follow-up survey has been launched to explore real-life experiences of adrenal crisis in greater depth, including barriers to timely treatment and areas for improvement in care. Achieving a large number of responses (targeting at least 1,000 participants) will help generate robust evidence to inform practice and policy. This work is especially important as it is being conducted alongside parallel studies exploring the perspectives of clinicians working in emergency care and endocrinology, providing a more complete picture of where improvements are needed to enhance patient safety and outcomes.

Self-injecting can reduce the chance of hospital admission!

Compared with needing help from emergency services, self-injecting is linked to a much lower risk of being admitted to hospital.

Chance of being admitted to hospital



Key message:

Being able to self-inject can make a real difference. It's linked to a lower chance of hospital admission and highlights the importance of training, confidence, and practical support.