

Cortisone-loop is an educational tool, which helps ensure the quality of care for children with adrenal insufficiency.

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Aim: To standardize the national quality of education for children and their families in understanding the disease of adrenal insufficiency and managing cortisone treatments in different conditions.

Background: Adrenal insufficiency is a severe condition which occurs for numerous different reasons. Diseases often require a period or even a lifelong treatment of cortisone and/or mineralocorticoid. Ensuring that families of patients who suffer from adrenal insufficiency have a high level of understanding and knowledge of the disease from the outset is key to them comprehending the severity of the disease, which in turn increases the chances of good compliance to treatments throughout the life of the patient.

Incomplete knowledge and education of the disease could lead to the patient's life being at risk in certain situations such as: Infections, trauma, etc...

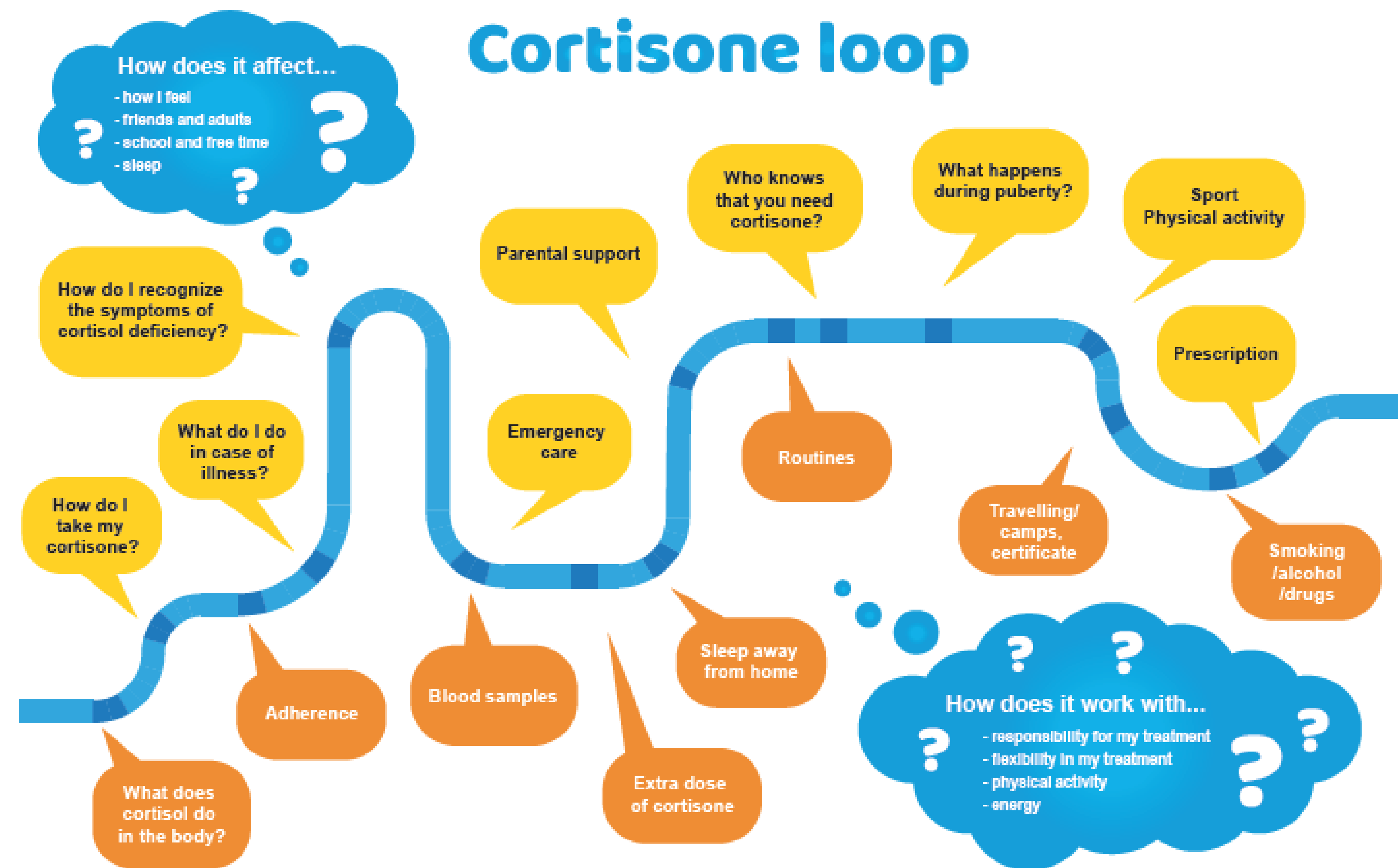
Patient care in Sweden is divided between University and county hospitals. The county hospitals have less amount of patient capacity, as well as a limited amount of experienced personnel. The quality of patient care and the level of education of staff vary between hospitals. Data on impact of standardized education in adrenal insufficiency is lacking

Conclusion

Standardizing the education using the “worksheet” in all clinics across the country, will lead to an increase in the quality of patient care so that every patient will receive the same education/information regardless of experience of the staff at the clinic they are visiting.

Result The work was initiated by the national nursery group in paediatric endocrinology. The group worked out a worksheet to be used for the education of patients in all paediatric clinics throughout the country. The worksheet contains questions on both sides of a loop. The upper part has evidence-based knowledge to be given patients and families during their first visit to the paediatric clinic.

The lower part of the loop contains the most important questions to be discussed face to face with patients during their visits at the clinic. The backside of the “worksheet” contains facts to support the caregiver in the conversation with the patient/family. The “worksheet” should be used continuously during any follow-up meetings at the clinic.



How do I recognize the symptoms of cortisol deficiency: <ul style="list-style-type: none"> - Low energy - Hypoglycaemia - Tired/depressed 	Who knows that you need cortisone: <ul style="list-style-type: none"> - Information for preschool/school - For friends 	What does cortisol do in the body: <ul style="list-style-type: none"> - The body's "stress hormone" - Circadian rhythm - "Cortisone School"
How do I take my cortisone: <ul style="list-style-type: none"> - Cortisone capsule opens alt. swallowed whole - Hydrocortisone is available in tablet form - Long-time active preparations 	Physical activity: <ul style="list-style-type: none"> - Field day - Sport - Other activities - Injuries 	Adherence: <ul style="list-style-type: none"> - Don't want to - Forgotten medicine - If I missed – or if I take too much – what do I do - Take/be responsible for the medicine yourself
What do I do in case of illness: <ul style="list-style-type: none"> - Fever >38 double dose, >39 triple dose - Cold without fever – no change - Gastroenteritis with vomit/diarrhea when cortisone cannot be taken up – seek medical attention - Accident/trauma – individual treatment 	Prescription <ul style="list-style-type: none"> - Who is responsible for the existence of medicines and orders when needed 	Samples: <ul style="list-style-type: none"> - 17-OH curve - Collecting of urine
Emergency care: <ul style="list-style-type: none"> - Solu-Cortef - Medical ID - Necklace and cortisol card 		Routines: <ul style="list-style-type: none"> - How to remember
Parental support: <ul style="list-style-type: none"> - Need for counselor? 	Patient associations/info: <ul style="list-style-type: none"> - Addison Group - CAH Association - Medicininstruktioner.se 	Sleep away from home: <ul style="list-style-type: none"> - Sleep with friends - Travelling/camps certificates - Travel by yourself - Late nights