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Consensus

Group 6. Modalities and frequency of monitoring of patients with adrenal insufficiency. Patient education[☆]

Groupe 6. Modalités et rythme de surveillance au long cours chez le patient avec insuffisance surrénale. Éducation thérapeutique du patient

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Abstract

Patients with adrenal insufficiency require regular, specialised monitoring in order to optimise their replacement therapy, to detect signs of under- and over-dosage, and to examine for possible associated disorders (auto-immune disorders in the case of auto-immune primary adrenal insufficiency either isolated or as part of auto-immune polyendocrinopathy syndrome type 1; illnesses with underlying monogenic causes). The transition period between adolescence and adulthood represents an added risk of a breakdown in monitoring which requires particular attention from medical teams and coordination between adult and pediatric medical teams. It is essential to encourage patient autonomy in the management of their illness, notably their participation in treatment education programs, in particular programs that target avoidance of, or early treatment of acute adrenal insufficiency. The principal educational objectives for patients in such programs are: to be in possession of, and carry the necessary tools for their treatment in an emergency; to be able to identify situations of increased risk and the early signs of adrenal crisis; to know how to adjust their oral glucocorticoid treatment; to be capable of administering hydrocortisone by subcutaneous injection; to be able to predict and therefore adjust treatment to different situations (heat, physical exercise, travel) and to be able to correctly use the appropriate resources of the healthcare services. Other programs could also be developed to respond to needs and expectations of patients, notably concerning the adjustment of hydrocortisone dosage to avoid overdose in the context of chronic fatigue syndrome.

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Keywords: Consensus; Adrenal crisis; Addison's disease; Corticotropin deficiency; Adult; Children; Monitoring; Auto-immune polyendocrinopathy; Complications; Quality of life; Patient education program; Prevention

Résumé

Les patients insuffisants surrénaux doivent bénéficier d'un suivi spécialisé régulier, afin d'optimiser le traitement substitutif, en recherchant des signes de sous-dosage et de surdosage, et pour rechercher d'éventuelles maladies associées (maladies auto-immunes en cas d'insuffisance surrénale primaire auto-immune isolée ou s'intégrant dans une polyendocrinopathie auto-immune de type 1 ; maladies associées dans certaines causes monogéniques). La période de transition de l'adolescence à l'âge adulte comporte un risque de rupture de suivi qui mérite une attention particulière du corps médical et une coordination des équipes médicales pédiatrique et adulte. Il paraît essentiel de favoriser l'autonomie des

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[☆] SFE/SFEDP adrenal insufficiency consensus.

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patients dans la gestion de leur maladie, notamment en leur proposant de participer à des programmes d'éducation thérapeutique, en particulier des programmes visant à éviter ou traiter précocement l'insuffisance surrénale aiguë. Les principaux objectifs éducatifs sont les suivants : avoir sur soi les outils de sécurité ; savoir identifier les situations à risque et les symptômes d'insuffisance surrénale aiguë débutante ; savoir adapter le traitement oral par glucocorticoïde ; savoir administrer l'hydrocortisone par voie sous-cutané ; savoir par anticipation adapter le traitement aux situations particulières (chaleur, exercice physique, voyages, ...) ; utiliser de façon pertinente les ressources du système de soins. D'autres programmes pourraient être développés pour répondre aux besoins et attentes des patients, notamment concernant l'ajustement de la dose d'hydrocortisone, afin d'éviter le surdosage dans un contexte de fatigue chronique non spécifique.

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Mots clés : Consensus ; Insuffisance surrénale aiguë ; Maladie d'Addison ; Insuffisance corticotrope ; Adulte ; Enfant ; Polyendocrinopathie auto-immune ; Complications ; Qualité de vie ; Éducation thérapeutique ; Prévention

1. What are the methods used and the frequency of monitoring patients long-term in adrenal insufficiency?

R6.1: We recommend that adults with adrenal insufficiency have regular consultation by an endocrinologist at least once per year. Strong recommendations. Expert opinion.

R6.2: We recommend that children with adrenal insufficiency have regular consultation by a pediatric endocrinologist in a specialised center or reference center two to three times per year and more frequently in babies.

Strong recommendations. Expert opinion.

R6-3: In adults, we suggest clinical monitoring based on evidence of signs of over- or under-dosage, particularly for preventing the consequences of chronic overdose in bone, metabolic and cardiovascular parameters. For adjustment of glucocorticoid replacement, we do not recommend routine use of hormonal markers.

In children, we recommend clinical surveillance (growth, puberty) and examination for clinical signs of overdose or under-dosage. We do not recommend routine use of biochemical markers for adjustment of replacement therapy, except in congenital adrenal hyperplasia where we recommend regular assay of specific biochemical markers. In cases other than congenital adrenal hyperplasia, assay for ACTH is sometimes useful for evaluation of treatment compliance.

In adults and children, for adjustment of mineralocorticoid replacement, we suggest clinical surveillance (blood pressure, salt appetite, lower limb edema) and examination for biochemical signs of under-dosing (hyponatremia, hyperkalemia, elevated renin) or overdose (hypokalemia, undetectable renin levels or levels in the lower end of normal range).

Weak recommendation. Expert opinion.

Regular monitoring is necessary to evaluate the daily status of hormone replacement therapy, to identify the appearance of possible adrenal crisis and its cause, to examine for associated illness and ultimately to help the patient to better live with his illness [1].

1.1. Monitoring criteria

The objective of replacement therapy is to restore a state of health and a quality of life that is as close to normal as possible. At examination, the occurrence of acute episodes suggesting acute adrenal insufficiency need to be checked for and their cause, if possible, identified. Monitoring of patients is essentially by clinical signs to detect signs of glucocorticoid under dosage (fatigue, nausea, myalgia) or of mineralocorticoid under dosage (increased salt appetite, hypotension—especially postural) or signs of glucocorticoid overdose (weight gain, striae, skin fragility, amyotrophy, insomnia) or mineralocorticoid overdose (hypertension, edema).

Biochemical analyses carried out should include assays for plasma sodium and potassium (hypokalemia can reflect glucocorticoid or mineralocorticoid excess; hyponatremia and/or hyperkalemia can reflect glucocorticoid or mineralocorticoid under dosage). Filipsson et al. showed, in a large retrospective cohort study of 2424 adult patients with secondary adrenal insufficiency, that a dose higher than 20 mg/day equivalent of hydrocortisone was associated with an unfavorable plasma lipid profile with increased LDL cholesterol and triglycerides and additionally with an increase in waist circumference [2]. A

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