

Summary – Quality of Care Standard for Adrenal disorders

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The Quality of Care Standard for Adrenal Disorders describes the constraints and the problematic issues that became apparent from the survey of patients/ carers and healthcare practitioners. The outcome has been divided into two categories: disorder-specific and generic. The disorder-specific modules describe problems and constraints that apply to a specific adrenal disorder; the generic modules describe the problems and constraints that apply to all adrenal disorders. This summary explains the contents of those modules.

Disorder-specific modules

The disorder-specific module entitled adrenal insufficiency discusses the modules Uniform Stress Instructions and Residual symptoms and Comorbidity. Stress instructions are vital for patients suffering from adrenal insufficiency in order to prevent or deal with a life-threatening adrenal crisis. Many patients with adrenal insufficiency can experience residual symptoms and comorbidity, and it is important that both health care practitioners and the patients are fully aware of this, so that further diagnosis can be carried out with a view to improving the quality of the patient's life in both the shorter and longer term.

The disorder-specific module entitled congenital adrenal hyperplasia discusses the modules Care during the transition period and Treatment and follow-up for adults. Many changes take place in the daily lives of young people between the ages and 16 and 25. Young adults also become responsible for their own health issues during that period. A safe and clear transition process is of the utmost importance in that context. The care for adults with CAH is a matter for specialists: the correct treatment and follow-up must be carried out in order to avoid long-term complications and maintain the quality of the patient's lives as much as possible.

The disorder-specific module entitled Cushing's syndrome discusses the modules Residual symptoms and comorbidity and Treatment and guidance in the perioperative period. Patients with Cushing's syndrome have high levels of cortisol, and this can be the cause of various symptoms and comorbidity. Thorough investigation and treatment of those symptoms is essential. There must also be attention for the treatment and guidance of patients by a multidisciplinary team - before, during and after surgery – to prevent residual symptoms and comorbidity, and to optimize the outcome of the treatment.

The disorder-specific module entitled primary hyperaldosteronism discusses the modules Uniform Imaging and Uniform AVS tests. Imaging and AVS play an important role in any further investigation into the cause of primary hyperaldosteronism. That makes it very desirable to have uniform methods of testing and reporting so that tests do not need to be repeated.

The disorder-specific module entitled pheochromocytoma discusses the modules Policy and guidance in the perioperative period and Follow-up. Surgery is the only possible curative option for patients with a pheochromocytoma. Thorough preparation prior to the surgery ensures that any perioperative complications are reduced to a minimum. Extended postoperative follow-up must be assured in order to be able to detect any recurrence of the disease.

Generic modules

The generic module entitled Promotion of awareness and knowledge of adrenal disorders includes recommendations as to how awareness and knowledge of these disorders can be improved among both patients and healthcare practitioners. This is important from two perspectives: to reduce diagnostic delay and to be able to provide guidance to

patients and their close circle of family and friends. Adrenal disorders are complex and call for specific attention in the context of the organisation of care. This entails the organisation of the care for patients with adrenal disorders under both normal circumstances (chronic care) and in an emergency. The generic module entitled Organisation of care explains the underlying principles.

The generic module entitled Diagnostics provides insight into the factors that can influence biochemical and clinico-chemical endocrine diagnostics and into the current problems surrounding the measurement of steroid hormones in the Netherlands. Recommendations are made which could help resolve these problems in the future.

A large proportion of the patients with adrenal disorders want to work with their healthcare practitioner(s) to explore options for testing and treatment, and want to be actively involved in drawing up the treatment plan. A healthcare diary could provide a solution. The generic module entitled Healthcare diary provides an explanation of what a healthcare diary is and how it could be used in practical terms.

Medication plays a pivotal role in the healthcare provided to patients with an adrenal disorder. The generic module entitled Customized medication explains why it is so important that medication is always available, is supplied in the required personalized quantities and is – preferably – reimbursed in full by healthcare insurers.

It is important for patients with an adrenal disorder to participate in the labour market, because working promotes good physical and mental health and therefore has a positive effect on wellbeing and recuperation. Specific characteristics of the various disorders affect the patient's options for participation in the labour market. The guidance and organisation of care in the context of the patient's participation in the labour market can only be effective if it is fine-tuned between patients, healthcare practitioners, company health and safety professionals and employers. This calls for communication and collaboration on all sides. This issue is discussed in the generic module entitled Participation in the labour market for people with an adrenal disorder.

Further information about the AdrenalApp, AdrenalNET or Adrenals.eu can be found on the relevant websites.

Please visit
www.bijniernet.nl (Dutch)
www.adrenals.eu (other languages)

Specific queries can also be emailed to:
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