Quality of Care Standard supports healthcare practitioners and patients alike

Quite often, neither healthcare practitioners nor the patients know enough about adrenal gland disorders and their treatment. This can lead to serious health risks. The Quality of Care Standard for Adrenal Disorders is intended to help change this situation. Patients played a leading role in drawing up the document that was officially listed in the Register of the Dutch National Health Care Institute in September 2018.

The process of developing the Quality of Care Standard for Adrenal Disorders and the associated aids took over three years. Patients, informal carers, doctors and nurses reviewed each new version and added their comments. This was important, because they are the people who will ultimately be using the Quality of Care Standard to improve the health and life of patients with an adrenal disorder. The document explains to health practitioners and patients what 'good care' for someone with an adrenal disorder means. It also helps patients find the best way to cope with their illness and its consequences. Various aids have been developed to help healthcare practitioners and patients share in the decision taking about treatment on equal terms. This patient orientation makes the Quality of Care Standard for Adrenal Disorders a pioneering achievement in the domain of healthcare.

Work to be done
The true involvement of, and attention for the patient is firmly embedded in AdrenalNET, the ‘consortium’ that initiated the development of the standard. This knowledge consortium includes the endocrinology departments of the Dutch university hospitals and teaching hospitals, the Dutch Adrenal Society (Bijniervereniging) NVACP and the Dutch Pituitary Society (Nederlandse Hypofyse Stichting).

The results of a baseline survey - carried out in 2015 among patients, doctors and informal carers - made it clear that there was work to be done. "Because most healthcare practitioners are hardly ever confronted with adrenal disorders, it can take as long as twenty years before patients are correctly diagnosed", says AdrenalNET coordinator Johan Beun who himself has an adrenal disorder. "And that also means that you may have to wait for years before you see the right doctor and get appropriate treatment. Because of their lack of knowledge and skills, patients and healthcare practitioners were often unable to take the right action in emergency situations. Patients were either unable or too afraid to administer an injection if their tablets weren't 'working'. And even in hospitals there was not always someone available who had the right knowledge. Patients

Listing in the Register
Improving the quality of healthcare is an important aspect of the remit of the Dutch National Health Care Institute. That is why this government agency encourages doctors, patients and health insurers to join forces and describe what they think comprises 'good healthcare'. These descriptions of 'good healthcare' are then formulated in a quality of care standard. Quality of care standards have to fulfil strict criteria if they are to be listed in the National Health Care Institute's register. An important criteria is that healthcare practitioners, patients and healthcare insurers have to have collaborated fully in its contents. But that proved to be a stumbling block with regard to the Quality of Care Standard for Adrenal Disorders. The Association of Healthcare Insurers in the Netherlands was unable to make anyone available to work on this project for rare disorders. It is estimated that the number of adrenal patients in the Netherlands is between 5,000 and 7,000 (pop: 17 mln). The insurers were, however, eager to endorse the contents of the document. The National Health Care Institute therefore decided to accept the Quality of Care Standard for Adrenal Disorders for listing in the Register. This is a public register and available for those who can read Dutch.
sometimes waited in the emergency room for a long time without being given the correct treatment. A risky situation."

With the aid of the Quality of Care Standard for Adrenal Disorders, AdrenalNET aims to improve the diagnostic process and the treatment, health and quality of life for patients. The document is intended to help avoid future recurrences of the problems that came to light as a result of the baseline survey.

**Infographics, mini-documentaries and animated clips**
The Quality of Care Standard for Adrenal Disorders is impressive for several reasons. The content of the document is significant, covering 200 pages. Many parties (see inset) and people have put a lot of time and effort into the project over the course of the three year development period. There were also financial challenges to be overcome. "In the beginning we rather underestimated what would be involved in drawing up something like this", Johan admits. "But thanks to everyone's belief in the project, and their hard work, we managed to get it done. A special word of thanks has to go to AdrenalNET’s secretary, Alida Noordzij, endocrinologist Lisanne Smans and Ad Hermus, professor of endocrinology and chairman of AdrenalNET. They were sometimes quite literally working day and night on the contents of the Quality of Care Standard."

The most impressive aspect of the document is therefore its contents. The Quality of Care Standard consists of five modules, each of them focussing on a single adrenal disorder. Each module contains specific information which is important for the care and counselling of patients with that particular disorder. Six general modules cover subjects such as improving knowledge about adrenal disorders, how healthcare is organised, diagnostics and customised medication. Another section looks at the participation of adrenal patients in the labour market, a domain in which patients often find themselves at a disadvantage. There are also special patient versions of all these modules. Attention is also given to the translation of the Quality of Care Standard in practical terms. For example, AdrenalNET has produced infographics, mini-documentaries and animated clips which present information about the various disorders in a way that everyone can understand. E-learning modules have also been developed so that nursing staff can improve their knowledge of adrenal disorders.

**The Quality of Care Standard for Adrenal Disorders in the Netherlands came about thanks to the cooperation and support of:**
- BijnierNET / AdrenalNET;
- the National Working Group of Endocrine Nurses (LWEV);
- the Dutch Association for Internal Medicine (NIV);
- the Dutch Endocrine Society (NVE);
- the Royal Netherlands Society for the Advancement of Pharmacology (KNMP);
- the Dutch Adrenal Society NVACP;
- the Dutch Association for Clinical Chemistry & Laboratory Medicine (NVKC);
- the Dutch Association for Urology (NvU);
- the Dutch Association of Surgeons (NVvH);
- the Dutch Association of Neurosurgeons (NVvN);
- the Dutch Pituitary Society.
Continual revision
According to Johan, listing in the Register is just the beginning. "If patients and healthcare practitioners do not use the standard, we will have done all that work for nothing. So we are organising regional meetings in different parts of the country to introduce the standard to both patients and healthcare practitioners. And it doesn't stop with simply providing information: we also try to make concrete arrangements. About how we are going to ensure that patients receive instruction about how to administer an emergency injection, for example. We encourage hospitals to follow the guidelines given in the Quality of Care Standard. The fact that the standard has been included in the National Health Care Institute's register certainly helps in that respect, by giving it more authority. After all, it had to fulfil strict criteria and go through an independent review before it could be listed. We are also helping to find ways in which university and regional hospitals can support each other to provide the best care for patients, 24 hours a day and 7 days a week. Ultimately we want to be able to reveal which hospitals are working according to the standard and which aren't. Patients will then be able to make a better choice of which hospital they want to go to for treatment."

Johan insists that the contents of the Quality of Care Standard for Adrenal Disorders are not carved in stone. "Patient associations told us that the patient versions of the modules were not completely appropriate for the information needs of their members. So we rewrote some of the texts and included a lot of supporting illustrations, and we will continue to revise the standard to satisfy new needs and requirements."

Further information about the Quality of Care Standard in the Netherlands?
Please contact AdrenalNET at INFO@ADRENALNET.EU
Details of this registration can be found at (sorry only in Dutch):
https://www.zorginziekt.nl/bibliotheek/bijnierziekten/Paginas/Home.aspx