

Aim: To create and implement a standardized program to be used to educate and train personnel in the proper management of GH-treatment. To create a standardized program for the education of the patients and their families, increasing their understanding, leading to greater adherence

Background: Since the 1980s, growth hormone (GH) treatment has been administered to children as daily subcutaneous (sc) injections.

The key to good adherence and successful treatment results is the patient's understanding of the growth/metabolic problem and the effect of GH. Without the high level of education and training, there is a high risk of a poor treatment response and therefore a waste of time and money for the family and community.

Sweden is a big country, from South to North it stretches 1572 km. Patient's care is divided between University and county hospitals. County hospitals have a smaller number of patients, as well as a limited amount of experienced personnel. The quality of patient care and the level of education of staff varies between departments and hospitals. Data on the impact of standardized education in GH-treatment is lacking.

Conclusion

The nationwide unified training given by the endocrine nursery team could improve the adherence and effectiveness of GH-treatment.

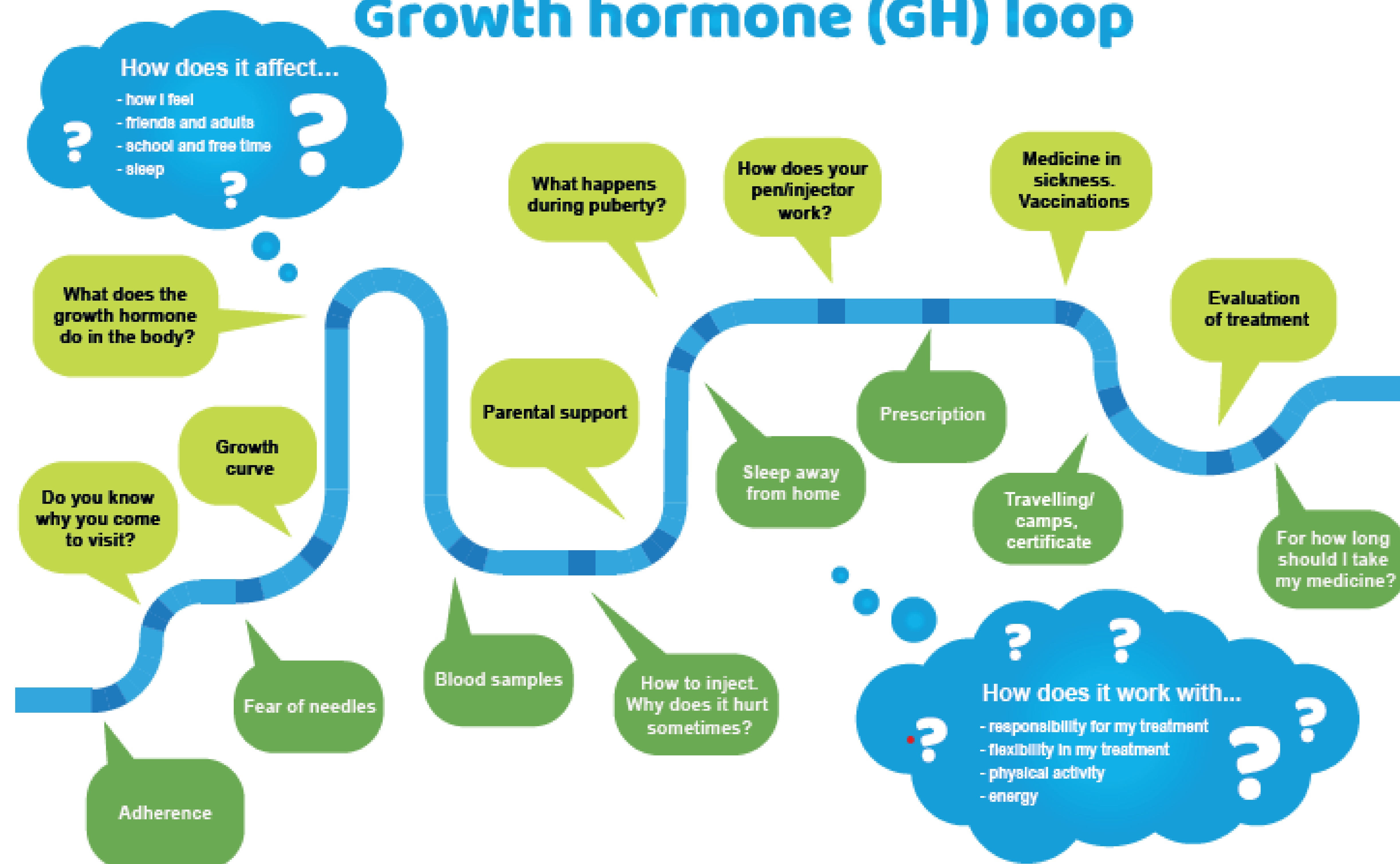
Implementing the proposed training materials will mean that every patient will receive the same high-quality care and patient education regardless of where they live.

Result: The National pediatrics endocrine nursery group have initiated this project to produce "worksheets" that can be used for standardized education in GH-treatment throughout the country. The result of this is a "worksheet" which includes a flow-chart containing questions on both sides of 'the loop', dividing the worksheet into two parts.

The first part contains fact-bubbles with questions and talking points related to evidence-based knowledge which patients and family have received education on during their visits to the pediatrics clinic.

The second part contains the questions that were asked face-to-face with patients during their visits to the clinic. The backside of the "worksheet" contains facts to support the caregiver in the conversation with the patient/family. It is intended that this "worksheet" should be used continuously during any follow-up meetings at the clinic.

Growth hormone (GH) loop



What does GH in the body do:

- Do you know why you get GH (age-appropriate info)
- What's more (except GH) affects growth

Adherence:

- Don't want to
- Forgotten injections
- If I missed in the evening
- Or if I take too much
- How to remember
- Take/be responsible for the medicine yourself

Sleeping away from home:

- Travel/camps/certificate
- Storage of the medicine

Do you know why you come to visit:

- Follow-up
- Possible side effects
- Diet
- Toilet habits

Blood tests:

- Why do we take blood samples and what do we look for

For how long should I take my medicine:

- Transition – adult

How does your pen/injector work:

- Time for injection
- Storage/durability

How to inject/ Why does it hurt sometimes:

- Place for injections
- Why do you get skin pits
- When to inject/create a routine
- Night out (teenagers)
- Who gives the injection
- Hassle of injection
- Gro Assist – Pfizer

Responsible for recipes:

- Order prescription in advance

Patient info:

- Medicininstruktioner.se