

Education to parents to give
necessary medical care at home.

Instructions for parents
Why is it that we want to teach
parents in Holland ?

Reasons: short or long term expectancy the child needs special medical care.

Instructions that are given vary:

- Some instructions can be given by paediatric nurses on the ward before the child goes home;
- Some instructions are given by the nurse together with support team
- Some instructions are so complex & high risk that the instruction is support at home performed by a specialized team.

Reason we have instruction plans

- We want to make sure the parents follow all the steps and understand what to do and how to do it . Aim less stress and fear.
- It's clear to all professionals involved, which step the parent has taken and what he still has to learn.
- By law we have records that show how the instruction took place and that the parent is competent.

Example of complex care TPN done by a specialized nutrition support team Reason:

- Obtaining of experience in the treatment and follow-up of children who are dependent on TPN is difficult
- Children should be treated in centres that have the experience with the treatment of TPN at home.
- Netherlands has 2 nutrition support teams:
 - 1 in the Academic Medical Centre in Amsterdam (AMC) and
 - 1 at the University Medical Centre in Nijmegen (UMCN)

Parents who have to do more procedures and get other care takers to continue support at home get a book with instructions

per procedure : Example baby with chronic lung disease

Example multiple procedures

- 1. Oxygen delivery (steps in care, instruction on technical aspects, safety etc.**
- 2. gavage feeding;**
- 3. Lung medication;**
- 4. Saturation monitor;**
- 5. Resuscitation (medical procedure is given and signed by MD)**

Example of instructions nurses give but does not mean they aren't supported by other teams

- Bladder flushing
- Bowl flushing /stoma care
- Broviac/Hickman catheter
- Gastrostomy tube /PEG-catheter
- Gavage feeding
- Tracheostomy care
- Oxygen delivery
- Medication

CHECKLIST parent instruction bladder flushing :

The instruction consists of the following items:

- The parent/caretaker has received the written protocol and understands the procedure and the method.
- The nurse shows the procedure step by step to parent/c.
- The parent undertakes the procedure step by step under supervision of the nurse. (min 2 times)
- The parent/c the does the procedure step by step while the nurse watches and checks if the parent is competent enough to do the whole procedure (min. 2 X)
- The parent/c can the discuss possible problems & complications and knows how to solve them .

I'll show you an example as they are in DUTCH
and no time to translate

- Example bladder flushing

Any questions ?