



Parent support and children with PID

Advice to parents with teenagers
– personal point of view

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Parenthood mission:

Get the teenager ready to fly on their own



Parents' role most important

- Research shows that the way parents deal with the healthcare system, disease and treatment, and their understanding for their teenager, is of greatest importance for how the teenager will go through these difficult years with a good compliance of their treatment.



Give freedom

- Let your teenager live her/his life as normal as possible.
 - Our philosophy: **You can do everything but sometimes in a different way.**
- Don't instinctively say **NO**, instead: say you will think about it.
 - School trips or studying abroad: Contact NMO in the country, letter from doctor, bring medicines etc, check insurances.
- Some times it is worth doing things even if you risk to catch an infection....





Knowledge and support

- Own knowledge about the disease is crucial.
- Important that the teenager gets information about the disease (from doctor and nurse) regularly and adjusted to maturity. Easy to forget if they have had the PID since childhood.
- Make sure that your teenager is offered **psychological support!** Nurse or doctor should inform about this possibility every year!
- Also ask for psychological support for yourself if needed.



Involvement and respect

- It's important that teenagers step by step take more control over the disease themselves.

- Meet the doctor alone

- Responsibility for treatment

- at 7pm,

Still need support. A balance act....

- Be RESPECTFUL: listen and ask what they need from you.

Brochure with useful information

from Denmark, written by Lotte Vosmar Denning

- available in English!



For parents:

- Acceptance
- About what it means to be a teenager/development
- Challenges for teens with a chronic disease
- Advice on what you can do as a parent (some examples):

- Give hope, show trust, get insight and knowledge and share with your teenager, show honest interest in your teenager's life, offer your help, allow teenagers involvement and own responsibilities

For teenagers:

- Good things to know about your disease
- Education and work
- Acceptance
- Travels
- Transition to adult care
- Useful links to learn more

NMO's role as support

- Offer knowledge and provide information.
- Offer arenas where parents and teenagers can meet (family camps, meetings, lectures, social media groups)



"Fun camps when I was a kid where I got understanding for my disease. I have got help to survive and a better future than I would have without PIO."

Parenthood mission:

Get the teenager ready to fly on their own

- Preparation is the easy part, letting go is the difficult part...
- Challenge for parents to lose control. It's good to practice because one day, sooner than you know, you will lose all control. That's a fact.

