

Sharing treatment responsibilities

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The amount of responsibility children take on regarding self-care and management of their condition can be a risk or protective factor [for adaptation]. Inappropriate expectations from adults about responsibility are associated with poorer compliance with treatment and poorer health status. If expectations are too high, this may place too many demands and too great a burden on the child, but if the child is given too little responsibility, this may undermine their abilities and may lead to resentment. Those who are able to take on appropriate responsibility and have control of some aspects of treatment are likely to have a greater sense of control, higher self-esteem and therefore better adjustment.

- Edwards & Davis (1997). *Counselling children with medical conditions*

Sharing treatment responsibilities

- Percentage of shared treatment responsibility
 - 20% at age 4-7
 - 30% at age 8-10
 - 35% at age 11-14
- Percentage of treatment tasks performed solely by parents
 - 70% at age 4-7
 - 55% at age 8-10
 - 35% at age 11-14

Treatment responsibilities

Adaptation framework

Consideration of a child's

- Understanding of their body, illness, treatment
- Emotion regulation
- Motivation
- Personal Experience

Children age 2-6:

Understanding of body, illness, treatment

- “Pre-logical”
- Egocentric (ie understand everything in relation to themselves)
- Illogical reasoning
- Illness caused by magic or punishment
- Can link treatment to illness because they often occur together
- Cannot understand permanence or chronicity of illness

Children age 2-6:

Treatment responsibilities

- Parents have sole responsibility for CF cares.
- Parents need to absorb anxiety about CF so child does not feel anxious.
- Need to build CF care into normal routine.
- Children need warmth, understanding, & limits in order to feel secure.
- Set clear expectations for the child, clear guidelines as to what you will do, what they need to do.
- Focus on what you would like to see, not what you wouldn't.

Children age 7-11:

Understanding of body, illness, treatment

- “Concrete-logical”
- Better at cause & effect
- Can use mental images eg imagine internal organs
- Rely on experience and trial & error
- Can interpret explanations literally
- Cannot think ahead & need help to proactively problem-solve
- Can understand that treatment contributes to health
- Prevention is very difficult to understand

Children age 7-11:

Treatment responsibilities

- See & acknowledge health-positive behaviours
- Can introduce self-responsibility for some treatments eg creon
- To teach new tasks
 - Break down into small steps
 - Begin at achievable point
 - Reward success, give opportunities to practise skill
 - Gradually move through small goals until final task achieved
 - Reward end result or effort towards the skill, even if not perfect

Children age 12+:

Understanding of body, illness, treatment

- “Formal operational”
- Abstract/hypothetical reasoning
- Ability to think ahead
- Focused on here and now
- Impulsive, difficulties regulating emotion well
- Assert independence, rely on peer group

Children age 12+:

Treatment responsibilities

- Adult-like collaboration, focused on relevant goals
- Building motivation, especially for preventative health care
- Need to listen rather than making assumptions of knowledge
- Independence does not mean adherence
- Non-adherence as an attempt to deny reality of CF
- Interventions focused on communication and conflict -> more effective than education alone

Shifting treatment responsibilities

- More treatment independence with age
 - Does not necessarily equate with good technique, adherence
- Agreement on level of responsibility (parent & child) predictive of adherence
- What is your child currently capable of?
- How do you know what they are capable of? (perception vs fact)

Change back! Reaction

- Change is uncomfortable.
- Not uncommon for adolescents to resent the change of responsibility, and they can react in common ways:
 - Complain parents do not care
 - Tune out & let parents do all the talking and health decision-making
 - Refuse to have anything to do with CF and treatment
 - Demand independence, “freedom” from parental reminders / involvement
- Conflict is a target for psychological intervention, due to the link with non-adherence

When does a child or young person need extra help?

- Increased complexity of treatment regime
- New diagnosis eg CFRD
- Times of stress / emotional overload
- Mental health issues
- May also need help when well