

When chronic illness is a child's reality...

What can parents do to manage and transform inevitable stressors.

The Child & Adolescent Psychiatry Practical Review
APRIL 2024, Friday 2.15-3.15PM
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In this session

- Chronic illness — the child's experience/ the parents' experience/ often different and even conflicting.
- What to do with stress—manage, name and tame.
- Tools that help both child and caregivers.

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Chronic

persisting for a long time, continually re-occurring; not easily changed with time or over time.

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Factors that color experience

- Is chronic illness static or progressive — or unsure?
- Is chronic illness life threatening or life changing or "just life"?
- Is chronic illness a surprise/ new experience— or familiar, familial?
- Are there resources to manage illness/ or are resources scarce or restricted?
- Are we alone with this— or is there a community?

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Chronic illness in children/teens

Child perception

- Body pain, discomfort that stays— adjust.
- Why me to it's me; accommodation to reality.
- Development persists— new demands and new interests.
- Adaptation may be compromised but rarely arrested.

Parent perception

- Shock and disbelief, grief.
- Determination to fix this— resource seeking.
- Illness feels bigger than development; losing sight of changes, new needs.
- My child is sick vs, my child has sickness and is so much more.
- Fear of future.

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We are in this together...

And parent and child are different...with often conflicting needs and desires.



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Helping parents name their own worries.

- * Start with “how are you managing?” and permit parents to have emotional space to grieve. No one plans for a chronically ill child.
- * When parents cannot go there, pay attention for opportunities to show them they can/ strong sense of mission to fix can cause them to lose sight of themselves, one another.
- * Sometimes fears are so intense— but also unrealistic—that not naming these can block their effectiveness. Sometimes fears are realistic.

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Helping parents access facts

- * Internet diagnoses’ prognoses.
- * Settling into a plan — and making sure that support is part of that plan.
- * Searching for options, and second opinions (without fear of hurting providers’ feelings).
- * Making room for questions.

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Helping parents see their child —all of their child.

- * Development still happens and that can be life affirming.
- * Even when illness is grim, finding the delight of growth and change.
- * Keeping perspective— and valuing fun, delight.
- * Paying attention to what my child likes, wants.

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Illness is a felt experience

- * And bodies can know what minds don’t, yet.
- * Children can have precocious sense of what is happening in my body (but no one asks them).
- * Helping parents ask the child what works— share the responsibility.
- * Pay attention to what the child resists— and know this is what is hard/ needs more support.

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Listen to the child’s wishes

- * Negotiate is the way to manage hard times— and gentle insistence when necessary. Be honest
- * Hear the child’s worries and fears — avoid false reassurances or promises.
- * Allow the child to imagine the future.
- * Work on mastery.
- * Wanting to be like everyone else— how to respond kindly.

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D A M

DANGER > ANXIETY > MASTERY

A universal formula

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Merging physical health with mental health

- * While physical health involves bodies, we know the mind/body connection is significant.
- * Chronic illness is always a strain on mental health.
- * Be honest about the overlap, and then benefits of support and a place to complain.
- * Supportive therapy cannot fix either, but it can be a comfort and company.

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When chronic illness is a mental health one.

- * Dealing with body reactivity — and behavioral manifestations.
- * Dealing with progression, as developmental stressors wax and wane.
- * Dealing with wishes to be normal, the same as others— and using denial to make it so.
- * Challenge of teens not knowing their own minds.
- * The problem of teens not being able to trust their own mind

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Examples from your work/ helping families cope with chronic illness.

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Thanks

These families need us a lot.

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