

Mental Health and Relationship Advice for Caregivers

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Overview

- Taking care of yourself
- Taking care of the family
- Taking care of your relationships

Self-Care

- Increased rates of parental emotional distress
 - 50% report moderate to severe anxiety or depression.
 - Correlated with parental ratings of child's physical health and emotional adjustment.
 - Guilt associated with genetic disorder.
 - Up to 40% report they “frequently” or “always” think that they should be doing more for their child.
 - Up to 86% report they “frequently” or “always” worry about what the future holds for their child.
 - Up to 69% report stress about meeting care demands of child and other responsibilities (work, etc.).
 - Up to 62% report they do not have enough money to take care of their child.

Self-Care

- Anticipatory grief
- Around 70% of parents reported lack of information about:
 - Options for sons in the future
 - Leisure/social
 - Career/employment
 - Availability of services
 - Professionals who can play a role in son's care
 - Support for parents

Self-Care

- Social development and support network:
 - Actively pursue friendships and social activities, even when it is a burden.
 - Don't be afraid to ask others for help.
 - Get involved in NMD community
 - Connecting
 - Advocating
 - Fundraising
 - Mentoring

Self-Care

Preventing burnout:

- **Moms**

- Take time for self
- Give yourself grace, focus on “good enough”
- Cut the cord

- **Dads**

- Develop a hobby
- Exercise
- Share roles/responsibilities

Seek professional help if needed! (before things get really bad)

Self-Care

- Don't let NMD define life
- Bitter parents cause bitter children
 - Try to find something positive about NMD
- Social Media
 - Positive: Good support network
 - Negative: See others doing better
 - Negative: Toxic attitudes, trolling

Family Care

- Behavior problems are stressful on EVERYONE in the family
- Extended family may not understand
- Caring for Siblings

Improving Parent Relationships

- Basic Principals
 - Relationships take work, can't be just based on "feelings"
 - People spend 4+ years at university preparing for a job, but spend little to no time preparing for marriage/relationships
 - Many people do not have a good concept of a healthy relationships
 - Expectations too high or too low
 - Rely on unhealthy models they grew up with
 - Stress of NMD will magnify any existing relationship problems.

Watch out for...



Everyone argues, but work toward a solution/resolution, not a “victory”...

- Criticism (attacking someone’s character)
 - Contempt (belittling, invalidating)
 - Defensiveness (denying, minimizing, justifying, blaming others)
 - Stonewalling (shutting down communication)
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- -John Gottman

Watch out for...

- Unrealistic expectations of partner
 - They should know what I need/want without me having to tell them.
- Sacrifice partner relationship to focus on kids/NMD
- Guilt/blame about carrier status

Grief

Diagnosis of DMD causes a grief reaction.

Different grief types:

Ignore the problem

Pillar of Strength (No outward emotion)

Workaholic

It's Not Fair! (Anger)

Change the world

Let's Process

It's the End of the World as We Know It (and I don't feel fine)

Grief

- Grief styles may change, timing may not “match”
- Different grief styles/timing may cause feelings of alienation, resentment, isolation.
- Different grief styles may not “work together”:

Let's Process vs. Ignore the Problem

It's Not Fair vs. Pillar of Strength

End of the World vs. Change the World

Other factors

- NMD is financially straining in the best of circumstances
- Overly-rigid roles

Teamwork

- Acknowledge that NMD is the enemy, not each other.
- You are stronger as a team, working together.
- No one understands what you are going through like your partner does.

Adjust Expectations

- Allow for different grieving styles
- Be extra patient, provide more grace
- Focus on being/expecting “good enough”

Connect

- Make partner your priority
- Humor
- Set short-term and long-term goals

Communicate

DO

- LISTEN
- Validate feelings
- Respect their concerns, even if you disagree
- Paraphrase what they are saying
- Ask questions for information (not to make a point)
- Acknowledge mistakes, apologize
- Forgive
- Use “I” statements
- Work toward compromise

DON'T

- Focus on winning
- Attack their character
- Belittle their concerns or ideas
- Listen only enough to point out how they are wrong
- Tell them what they should have done
- Make global statements (“You ALWAYS...”)
- Go radio silent