



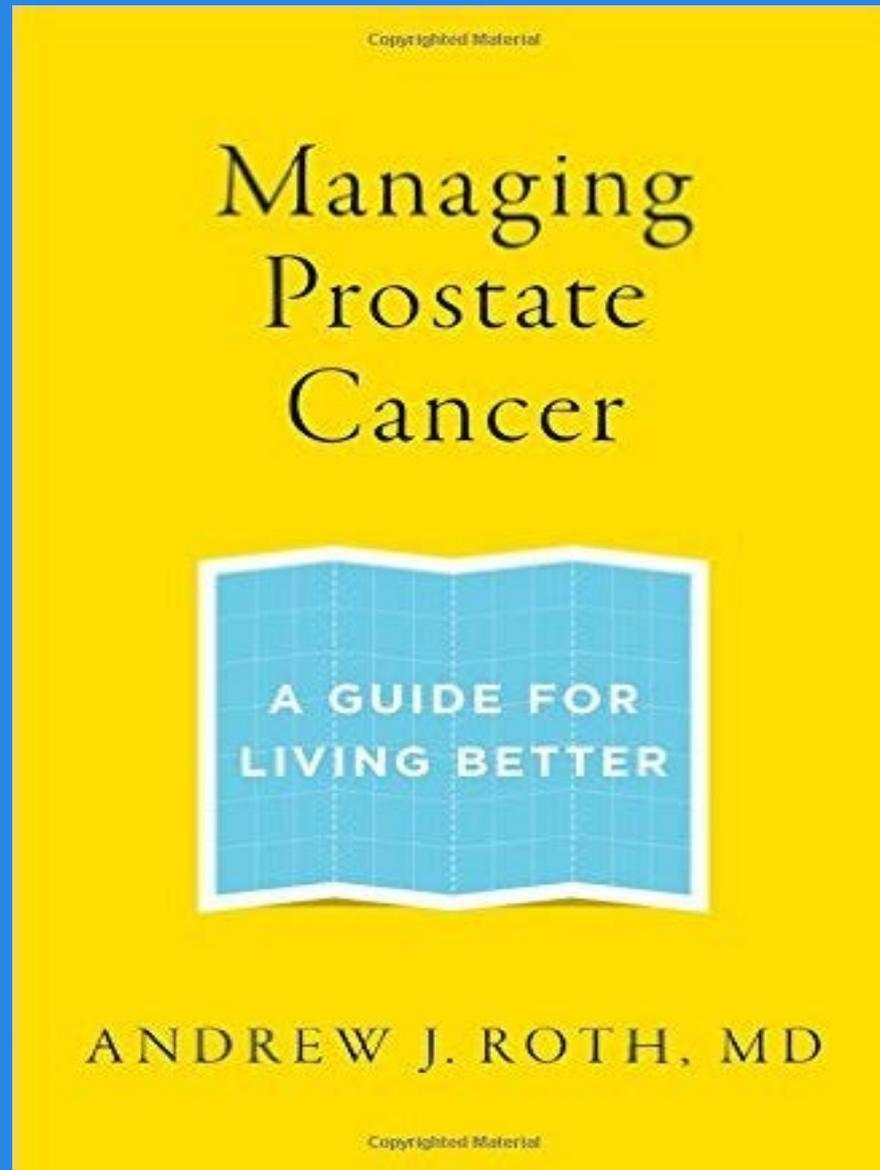
Memorial Sloan Kettering
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Psychological Effects on the Chronically Ill and Their Families

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Disclosure



Let's Get Started

- A chronic condition is a human health condition or disease that is persistent or otherwise long-lasting in its effects, but without an accurate crystal ball.
- Focus on symptoms vs illness control vs cure
- One disease does not describe all affected by it:
 - Long bone involvement
 - Chronic uncontrolled inflammation
 - Extraskkeletal: kidney, skin, brain, lung, heart
 - Bone pain: lower limbs, knees and ankles; lower back and stomach pain
 - Diabetes insipidus
 - Ataxia
 - Dyspnea
 - Kidney failure
 - Hypopituitarism
 - Liver failure
 - Problems with coordination, slurred speech, behavior disorders, vision problems
- It's common to experience a range of emotions:
 - Guilt, anger, sadness, fear, anxiety and depressed mood
 - The roller coaster: accepting one day, and angry the next.
- Family members also experience emotional reactions



Treatment

- Surgical debulking
- Corticosteroids
- Cyclosporin
- Interferon
- Chemotherapy
- Vemurafenib
- Radiation Therapy



Triggers for Distress

- Blood tests
- Scans
- EKGs
- Anticipatory anxiety



Coping with a Chronic Illness

Coping Strategies

- Facing and accepting the diagnosis may take time.
- Ask your doctor what specific steps you can take to optimize your health.
- Active coping may help:
 - Take medications as prescribed
 - Eating better
 - Some activation is better than none (paced)
 - Continuing to socialize
 - Can you let go of unnecessary obligations, or ask for more help?
 - Build a support network you can rely on, and communicate with them about how they can best help you manage your disease
- Be aware of ups and downs of ‘positivity’ strategies
 - Focus on problems or emotions
 - What is ‘good-enough’?
 - Slippery slope of stability or ‘new-normal’



Chronic Illness

- Fatigue
- Pain
- Appearance
- Physical abilities and independence
- Impact on work and finances
- If stress, anxiety, depression and anger brought on by the illness are interfering with life, it is important to seek help and attempt to regain a feeling of control.
- Support groups might help:
 - To know you are not alone
 - To potentially learn some new tips on how to cope
- Improved management with more information (up until a point)
 - Make sure the information is reliable
 - It is important to find a health care provider that you can trust.



Social Cognitive Processing to Enhance Coping and Reduce Distress

- Reframe issues of illness (ie, loss)
- Problem solve daily challenges
- Put the past in a tolerable perspective
 - Life review to note strengths, manage anxieties
 - Using coping tools that worked before
- Increase social ties/new behaviors
 - To overcome loneliness
- Processing uncertainty about mortality
 - How to make peace with one's life/impart wisdom
 - Enhance sense of meaning and purpose



Social Cognitive Processing Theory

- Adjustment following adverse or traumatic events
- Proposes that an adverse event such as an ECD diagnosis and continued treatment can shatter a person's beliefs about him/herself and the world.
- For previously healthy older adults:
 - assumptions about mortality, body integrity, and ability to control their daily lives are challenged.
- For those with other pre-existing illnesses:
 - Illness challenges assumptions about control, while an additional diagnosis of ECD can crystallize fears of mortality.



Psychotherapeutic Flexibility

You don't need to be crazy
to get psychological help

- May need to decrease length or frequency of sessions
- May need to focus on physical and psychological symptom interplay and relief
- May need to be flexible with therapy style:
 - Education
 - Support
 - Cognitive-behaviorally oriented
 - Insight-oriented
 - Existential
- May need to have spouse/family member in session



Distress, Anxiety and Depression: Treatment in Psycho-Oncology

- Psychotherapy
 - Cognitive behavioral, supportive, insight oriented, Dignity, Meaning Centered psychotherapies
 - Reframing, progressive relaxation, guided imagery, meditation, hypnosis, behavioral activation
 - Understand the illness in context of life continuum
 - In-person: individual or group; or telephone counseling
- Pharmacotherapy
 - Benzodiazepines: Sedation, confusion, falls
 - Paradoxical agitation
 - Neuroleptics: Low doses effective; EKG; sedation; DM
 - Good alternative or addition to benzodiazepines
 - Antidepressants and Psychostimulants



Coping with a Chronic Illness

- Families:
 - It's not unusual for couples to experience strain on their relationship.
 - Try to see things from the other's perspective
 - Keep the lines of communication open
 - Plan for some alone time with your partner
 - Encourage your partner to make time to care for himself or herself
- Finding ways to help others and be a role model
- Groups vs individual therapy



Conclusions

- There is no ‘right’ way to coping with a chronic illness
- You may find new weaknesses and strengths
- Try to stay active physically and socially
- The ‘glass half full’ approach may lead you to ‘even fuller’
- Be aware of how others around you are impacted as well
- The old ways of coping and communicating may not work well now
- Get help if you are feeling stuck

