Dr. T's Formula for Thriving with CFS
(or SEID, Chronic Mono, ME/CFS, CFIDS, Yuppie Flu, etc)

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1. Don't believe all the advice you're given (including this list!!).

a. We are diverse group. Treatment affects each of us differently.
b. CFS is not just one illness but many. Unlikely to be one solution.

2. Don't sit around waiting for a CURE.

a. Difficult illness, not much research money compared to other illness. Progress will be slow.
b. You've got only one life. Don't waste it waiting.
c. If a cure comes along you will adjust just fine ☺. No need to plan.

3. Don't compare yourself to others who are not ill.

a. If you must compare, don't forget those who are less fortunate. Think-spinal cord injuries, devastating burns, severe depression, cancer, residents in nursing homes, 2 billion in poverty, etc. We're not the only ones with a loss. Would you really want to trade places with someone who is a political prisoner in Iraq?

4. Don't compare yourself to who you were before you got CFS

a. If you do you will be bitter and unhappy. (We're trying to go the other way, remember?)

b. Reminiscing is a bittersweet toxin and does not improve your illness and may contribute to unhealthy neuro activity worsening your condition. Suffering, self-pity, focusing on pain can become a learned behavior just like any brain activity that is repeated over and over. That means even if the painful stimulus resolves, you will continue to feel pain because your brain has ***learned to be in pain***.

5. Don’t try every pill/diet/manipulation/therapy/vitamin/supplement.

a. Every trial has an **economic** and **personal cost**.

b. *The Rollercoaster of Hope/Despair*. “ Ya Pay Yer Money and Go Fer a Ride!”

c. “*There is a fool born every minute*.” Not all providers have your best interests at heart.

6. Do Re-invent yourself.

a. Find out what you **CAN DO**. Start from scratch. (Pretend you were in a terrible accident and lost your arms and legs and your ability to talk and listen and think and feel and relate to others. Now a miracle occurred and you just got everything back, except you’re tired all the time. What would you do?)

b. Just as important, accept what you can’t do. (And get over it!) You may be able to return to it later. Just ask Rik or myself.

c. Look for examples of people all around us who have done just that successfully. Copy them. Use them as Role Models for your behavior. I’m sure they won’t mind.

7. Do try CBT. (It’s a 3-letter not 4-letter word.) Really!

a. CBT not a cure for CFS, but it can help your quality of life.

b. Works for cancer, bereavement, any human loss.

c. Example of alcoholic. Learn how not to start the self-pity process and how it can make you fell better about your loss.

8. Do Get Connected to others with CFS.

a. Email, phone, write others with CFS. They need you as much as you need them. You may learn something and be able to help.

b. Volunteer-at local school, library, community. (Can you do 30 min/week?)

c. Discover what activities you **can do** with friends. Plan these things as you lie resting. Don’t overdo but be consistent. One movie/lunch date per month? One email per week? Reap the benefits of staying connected.

d. When you visit non-ill friends, talk about your new activities (the music you are listening to or book you’ve read/listened to, the 2nd grader you’re teaching to read) not your CFS symptoms. Even YOU need a break from that!

9. Do apply for SSDI or disability insurance.
  a. You are legally disabled and entitled to SSDI.
  b. Apply, Be Rejected, Appeal, Repeat. Then Go Past Payday.

10. CFIDS is one Neurologic Illness that usually doesn't get worse with time.

a. Most other neurologic illnesses get worse over time. Symptoms of S.E.I.D tend to get somewhat better over time. Be thankful you don't have ALS,MS, brain tumor.

b. CFS/SEID does not seem to shorten life expectancy. (Even though some days we all wish it would!!). Every day is a Gift. That's why it's called The Present.