

Personal Cancer Survival Plan

Get Angry – Get Smart – Get Organized
Ten Steps to Surviving Cancer



Name: _____ Date: _____

This booklet was prepared by Norman J. Scherzer, Executive Director of the Life Raft Group.

This plan is based upon practical observations gained from my experience of keeping my wife alive with a rare cancer called GIST (Gastrointestinal Stromal Tumor) for 22 years after she was given six months to live, and hundreds of patient medical histories and stories that come across The Life Raft Group forums and medical databases. Although I knew little about cancer when I started, 25 years experience with the Centers for Disease Control and five years as the Assistant Commissioner of Health for New York City gave me a good foundation.

The focus here is upon the decisions that patients need to make in order to survive based upon what is currently known. Like all survival decision making, it may not have the luxury of waiting for tomorrow's research.

Of course, none of this information is intended to be a substitute for discussing cancer management and treatment with your physician.

1. I Will Create a Blueprint for Living



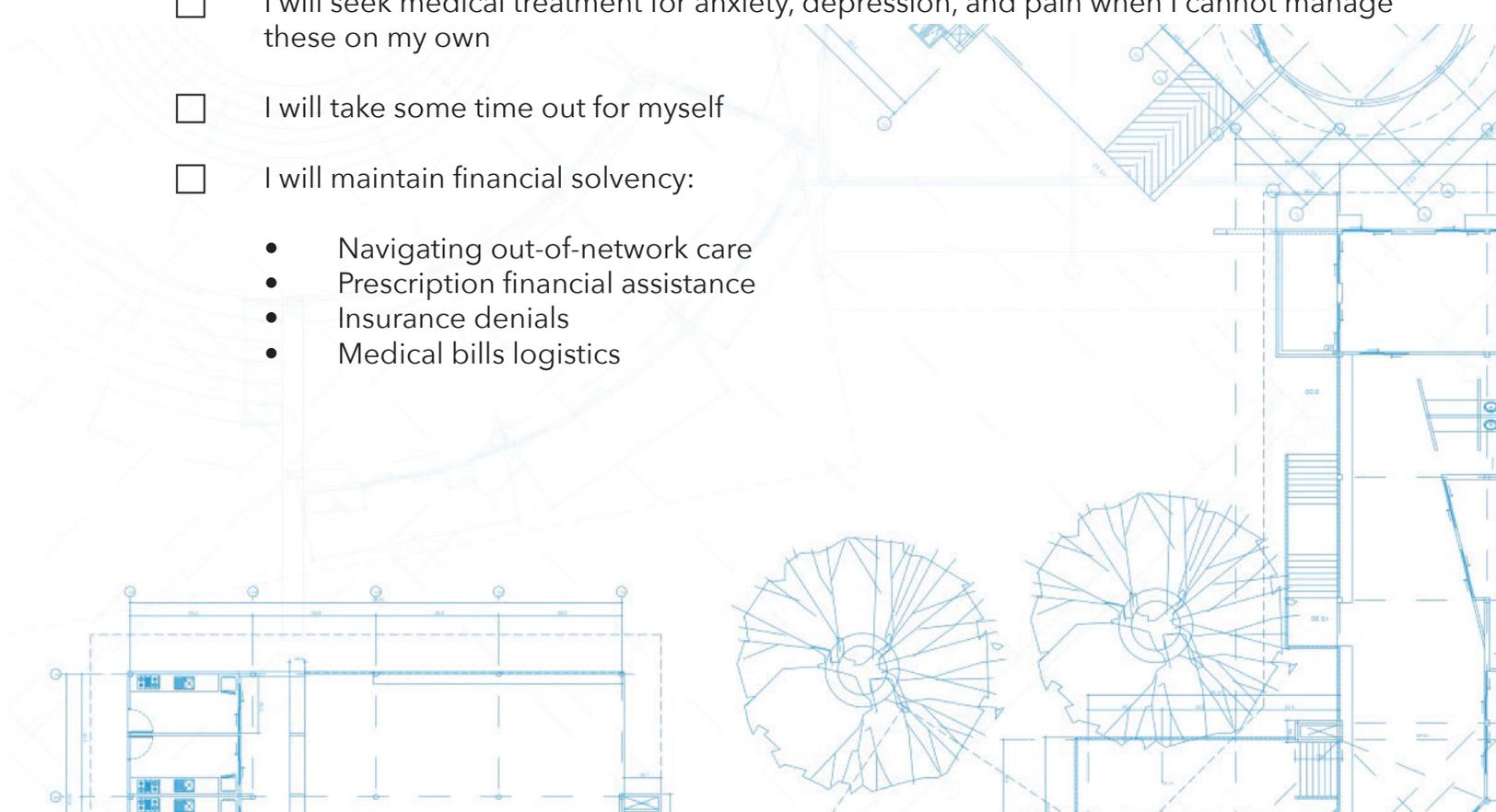
I will work to control my medical care

- I will negotiate timely test results appropriate to my personal anxiety level
- I will allow myself to be sad or angry, cry or laugh whenever I feel so inclined
- I will learn to say:
 - "I understand, but that is unacceptable."
 - "With all due respect, doctor, I would be more comfortable with a second opinion. Who do you recommend?"
 - "Doctor, are you prescribing a treatment that my insurance will pay for?"

I will decline to become a statistic

I will strive to retain control over my personal life

- I will live a healthy/balanced lifestyle, including exercise, self-reflection, and indulging myself with treats like chocolate
- I will always have achievable goals to look forward to no matter how small
- I will find my spiritual/emotional center and create ways to go there
- I will seek medical treatment for anxiety, depression, and pain when I cannot manage these on my own
- I will take some time out for myself
- I will maintain financial solvency:
 - Navigating out-of-network care
 - Prescription financial assistance
 - Insurance denials
 - Medical bills logistics





2. I Will Create a Support Network

- Personal Advocate: _____
- Caregiver(s): _____
- Specialist: _____

Particularly for a rare cancer

- Local Oncologist: _____
- Clinical Trial Oncologist: _____
- Family Doctor: _____

Who is my doctor?: _____

- Clergy/Spiritual Support: _____
- Support Group: _____
- Psychological Support: _____

Friends: (Cancer is one of the best ways to find out who my real friends are. When a friend offers to help, I will do that person a real favor and say yes.)

- Friends: _____



"It doesn't interest me what planets are squaring your moon. I want to know if you have touched the center of your own sorrow, if you have been opened by life's betrayals or have become shriveled and closed from fear of further pain!

I want to know if you can sit with pain, mine or your own, without moving to hide it or fade it, or fix it.

I want to know if you can be with joy, mine or your own; if you can dance with wildness and let the ecstasy fill you to the tips of your fingers and toes without cautioning us to be careful, be realistic, or to remember the limitations of being human.

It doesn't interest me who you know or how you came to be here.

I want to know if you will stand in the center of the fire with me and not shrink back."

- Mountain Dreamer Speaks

3. I Will Understand My Cancer



- I will understand where I am in the continuum of my disease
- I will check to see that my original diagnosis was confirmed
- I will learn what is known about the genetic profile of my cancer and what the relationships are, if any, between that determination and response to different treatments
- If my primary disease has not progressed to metastatic disease, I will learn about my risk factors

RISK FOR PROGRESSIVE DISEASE
GIST Cancer as an Example

		MITOTIC COUNT (HPF)		
		<5/50 HPF	5-10/50 (HPF)	>10/50 HPF
TUMOR SIZE (cm)	<2	VERY LOW	MODERATE	HIGH
	2.5	LOW	MODERATE	HIGH
	5-10	MODERATE	HIGH	HIGH
	>10	HIGH	HIGH	HIGH

- Resources
 - Pub Med (<https://www.ncbi.nlm.nih.gov/pubmed/>)
 - Clinical Trials (<https://clinicaltrials.gov/>)
 - Support Group - the era of the expert patient and the internet





4. I Will Advocate for the Right Dose of Drugs

- It is easier to prevent drug resistance than to reverse resistance once it occurs
- Side effects may get better over time
- Starting at a lower dose and escalating gradually to a higher dose helps to minimize side effects
- How clinical trials determine dosage levels: actual dosage vs. starting dosage (intent to treat)

"Our greatest glory is not in never failing but in rising every time we fail."

- Confucius

100mg

50mg

200mg



400mg

5. I Will Learn to Manage My Side Effects



- Many side effects get better over time
- Side effects change over time
- Dose escalation can reduce side effects
- Side effect management varies between individuals and sometimes can be reduced by:
 - Taking drugs gradually while eating
 - Varying the time of day (e.g. from morning to evening)
 - Splitting the dosage (with doctor approval)
- Many side effects can be managed with medications
- Some side effects can be managed with mind-body practices
- Some side effects can be lived with
- SideEQ: An online resource of the Life Raft Group

*"If you don't run your own life,
someone else will."*

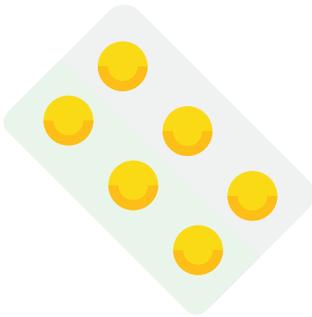
- John Atkinson





6. I Will Take My Medication

- I will adapt a reminder system that works for me
- I will speak to my surgeon about minimizing drug interruption prior to and following surgery
- I will reach out to the pharmaceutical company should I be unable to afford my medication
- I will keep a diary of those times I do not take my medication



"We are all inventors, each sailing out on a voyage of discovery, guided each by a private chart, of which there is no duplicate. The world is all gates, all opportunities."

- Ralph Waldo Emerson



7. I Will Learn How to Monitor My Treatment



- Tests
 - I will double check the orders for my tests
 - I will explore whether my drug plasma levels can be tested on a routine basis
- Record Keeping
 - I will write the questions I have for my doctor prior to my appointment
 - I will keep a medical diary
 - I will ask for and keep copies of any operative reports
 - I will ask for and keep copies of any pathology reports
 - I will ask for and keep copies of any CT Scan or other Diagnostic Reports (e.g. MRI, PET Scan, etc.)
 - I will ask for and keep copies of any laboratory reports. I will track laboratory tests. When new test results come in, I will double check that the reference range has not changed

Test Name (Reference Range)	Date	Date	Date	Date

Remarks: Try to note events that might have influenced a lab test; e.g. an infection that led to an elevated white blood cell count.





8. I Will Investigate Reports of Progression

- I will check to see if the same radiologist has read the latest report
- I will ask for a second opinion of any report of progression
 - False progression is not uncommon
 - Isolated progression may be amenable to surgery and may permit me to remain on drug
 - A drug may still work despite some progression
 - Mistakes do happen

"Life is a daring adventure or nothing."

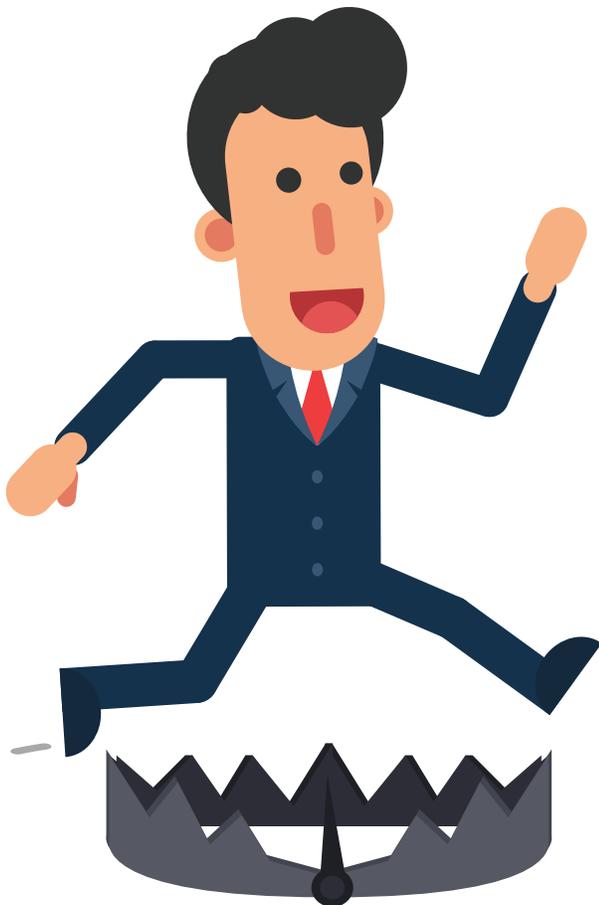
- Helen Keller



9. I Will Learn to Try to Avoid Things That May Do Me Harm



- Invasive tests and procedures that will not influence decision making (e.g. needle biopsies if surgery is indicated regardless of the results)
- Hospitals (1.7 million people acquire bacterial infections in US hospitals each year and 99,000 of those patients die as a result according to the CDC).
- Premature cessation of a drug prior to or following surgery
- Premature cessation of a drug until an alternative treatment is found
- Medical mistakes; they are quite frequent
- Invasive surgery unlikely to prevent recurrence
- Invasive surgery that will create lifestyle changes I cannot live with
- Negative family and friends



"The art of living lies less in eliminating our troubles than in growing with them."

-Bernard M. Baruch



10. I Will Learn Everything I Can About the Options for Treating Drug Resistance

- Surgery or other interventions for isolated progression may permit me to remain on a drug
- Crossing over to a higher dose after progression may be a prudent first step
- Clinical Trials
 - I will ask the oncologist recommending a clinical trial within his medical facility whether there may be more appropriate trials at other locations
 - I will ask the oncologist recommending a phase I clinical trial what he thinks is the dosage level most likely to confer efficacy
 - I will learn about the different phases of clinical trials and the use of placebos with and without a crossover to the real drug upon progression
- Off-label prescriptions
- Compassionate use
- Complementary medicine

"We are still masters of our fate.

We are still captains of our soul."

- Winston Churchill



I Understand That I Will Not Live Forever

(Please complete this page first)

All life is a form of progression to death and all our time is borrowed. When all available treatment has failed, I will decide whether to keep on living.

The one thing I have always wanted to do before I die is:

"Men spend their lives in anticipations—in determining to be vastly happy at some period when they have time. But the present time has one advantage over every other—it is our own. Past opportunities are gone, future have not come. We may lay in a stock of pleasures, as we would lay in a stock of wine; but if we defer the tasting of them too long, we shall find that both are soured by age."

- Charles Caleb Colton

