



SLYESTRONG #6
FOUNDATION



PLAYBOOK
OF RECOVERY

#GET HYPED FOR LIFE

How to Use This Book

The treatment for any type of condition is often long and involves various doctors' specialties, treatment facilities, clinics, medicines, and equipment. Hopefully most of the treatments, hospital stays, tests and medications are paid for by the individual's health care insurance. Patients are asked for a variety of medical insurance information from the moment they arrive at a doctor's office. Most have their medical card with them, but probably don't know much about the terms of their insurance. ***FIND OUT NOW!***

At the same time, generally under emotional stress, families begin to receive information concerning the condition of their loved one. This information is often fragmentary and incomplete but it is an indication of tests, procedures and timeframes to come. To fight this disease, people not only have to want to get better, they need to have an organized approach to the process. In our healthcare field today, modern medical technology is truly miraculous, but doctors and nurses are specialists, overworked and simply don't have the time to consult with other doctors who are also treating the patient. Someone else has to take responsibility for managing the patient's treatment process. That person is generally a spouse, a parent or an adult child. Yes, you can retain a patient's advocate, but it is both costly (not paid for by insurance) and they represent multiple individuals. You have to take management responsibility!

At the beginning of the book, there are pockets for blank note cards as well as business cards. Collect business cards from every doctor, treatment center, pharmacy, etc. Date each of them as you receive them. Using the note cards, jot down pertinent contact information, cell phones, etc. Completely fill out the primary contact sheet. Do the same for the notification sheet. Families, friends, and workers both need and want to know what is going on. Be proactive. Establish a small group that you give progress reports to and let them tell others. Create a group email list for weekly update. If you don't, you won't be able to manage the incoming calls.

Depending on the condition, the patient will be under the primary care of one specialist, but almost certainly, other doctors will be called in. It is critical that you LISTEN to what each doctor says and RECORD the information given at each appointment or consultation. Especially in the hospital room. The value of the book is finessing the flow of information between and among the medical profession. ASK each doctor to read the notes from other doctors concerning both treatment and medications. Record what happens after each treatment. This is especially important for the various medicines that will be prescribed. Keep a complete record for each doctor and show the other doctors. (Keep a medication form in each doctor's section) Drug interaction can be life threatening.

The types of information that is listed on these pages are familiar to all who have visited a doctor. Unfortunately, there seems to be a growing need for a book like this and the need to take charge of your own medical treatment. Use this book; you'll be glad that you did.



'A Record of Recovery'

The idea for a book such as this occurred when my son-in-law was diagnosed with cancer. The normal first reaction was disbelief, grief and dread. But once those initial reactions past, it was evident that there was going to be a long period of treatment involving a multiplicity of doctors and facilities.

The idea for this book came to me from a friend whose wife was under treatment for Parkinson's disease. He quickly came to understand that each of the doctors treating his wife was looking at the treatment from their own specialty and little thought was being given to the interaction of all the drugs and treatments on the patient. He quickly found out that *doctors rarely talked with one another* about his wife's treatment for no other reason than they never had done this before, weren't in the same practices or in other locations. After a severe seizure brought on by conflicting medications, he began to keep notes of all doctor recommended treatments and medication so that he could advise the other doctors of the team what course of treatment had been established. He even went so far as to initiate periodic conference calls with all the doctors in order to review the current treatment. It worked and his wife survived.

With my son-in-law, I immediately understood that his treatment, while primarily under the care of his oncologist would necessitate treatment from other doctors, disparate medical facilities and a wide range of medications. In addition, there would be routine consultations in the hospital, during office visits and with various treatments for chemo and radiation that in themselves would engender additional courses of action. First we determined that a caregiver would accompany him to all medical visits. Then, that individual would take notes. But then, the information had to be organized.

This book is nothing but blank forms divided by sections, one for each medical specialty, to keep a running account of the treatment plans. I included a business card holder for the multiplicity of medical personnel. All inserted into a three ring binder for ease of writing & copying. My daughter recorded information at each doctor's visit. It worked. Soon the doctors noticed it and asked to read the notes taken at other doctor's offices. It also provided information on the effects of the treatments and medication. Now my daughter is using it in her fight against ovarian cancer.

Both nurses and doctors have appreciated having a concise patient history available for review as the treatments progress. I call it a "Record of Treatment" and hopefully recovery.

Martin McDermott
~ *A loving Dad*



'In Sickness and In Health'

Just hours after returning from a two week honeymoon, we found ourselves sitting in the ER. For weeks, my fiancé turned husband had been complaining of a sore throat. Joe was lethargic, we just attributed that to all the wedding planning and celebrations. But his symptoms progressed. We saw 3 doctors; each proscribed an antibiotic and lozenges. So we played cards while we waited on the CT scan results. The ER was a buzz about "The Honeymooners", lots of laughing and joking around until it got eerily quiet. The doctor came in, pulled the curtain and said "Joe, *you have a very large mass at the base of your tongue. It's blocking 95% of your airway. It's probably cancer, a very aggressive form but we won't know until we biopsy it. Right now, we need to take you into surgery to insert a tracheotomy tube so your airway is not compromised.*" And in that instant, all the air was sucked out of the room and I could barely breathe.

We met with various doctors that weekend, it's all a whirlwind. I was in complete denial. My husband was 29 years old, an athlete in the best shape of his life. This had to be a mistake. But as they rattled off the symptoms on the questionnaire, all of which Joe replied "yes" my heart sank and my stomach turned. I went home, without my husband. My parents didn't know what to do, how to help. So my Dad created this "playbook" of recovery since my husband was a football player and now a football coach.

The days, weeks and months following were full of surgeries, appointments, chemo and radiation treatments. Countless prescriptions with crazy side effects. Specific insurance requirements and referrals necessary before anything could be scheduled or ordered. That was a level of frustration no one should ever have to endure while caring for a loved one. If it were not for this "playbook", I would have ceased to function. This "playbook" accompanied Joe everywhere. No matter whom took him to his appointments, he had a complete record of everything that had happened to date with him. It's scary to think about those patients that don't have an advocate acting on their behalf. The painful reality is that doctors don't talk, computer systems are not integrated and frankly nurses are overworked with very little time. This "playbook" gave me control over a powerless situation. It empowered me when engaging with the medical staff; I became an expert on Joe's condition and care. This allowed Joe to focus on Joe, to mentally prepare for the fight of his life. This made his disease an opponent that he could visualize and destroy!

This past June, we celebrated our 12th wedding anniversary. During this time I've been diagnosed with ovarian cancer twice and most recently breast cancer. This "playbook" has become a staple in our family. We turn to it whenever we hear of a family member, friend or stranger that is in need. Both Joe and I are in remission. We have been blessed with 2 amazing little boys, truly our miracle babies!

Joe was AJ Slye's football coach, mentor, and friend. The Slye family is our family and we are honored to be a part of the SlyeStrong#6 Foundation.

Heather Mangano
~ Survivor/Caregiver



'But You're the Mom, You're Supposed to Fix It'

The second week of December can seem like a very busy, yet exciting time. December 2012, was especially exciting because my oldest son, AJ was coming home from college for winter break. I was so excited, just wanted to get all the "other stuff" done and out of the way so we could have fun, family time finally being all back together.

When AJ got home, December 12th, he was complaining of a muscle spasm in his back. We all just wrote it off as tension from studying from finals and driving through DC traffic to get home. Two days later, he was still complaining of the pain. We decided to take him to Urgent Care for some kind of relief. When we got there, his pulse rate was extremely high, so they sent us to the ER. At the emergency room, they were unable to duplicate the high pulse rate, and were about to let us leave. Right then, the doctor came in and said there was something strange about his bloodwork. Five hours later, a doctor walks in and says, "We think your son has leukemia. You must go by ambulance to UVA Medical Center immediately."

We arrived at UVA, he went through more testing before we were even placed in a room. We had so many doctors, nurses, and specialists come in and out during those first few hours, I couldn't remember anything anyone was saying. It felt like a bad dream that was unfolding and I couldn't understand, let alone remember what they were saying. In the morning, the doctor confirmed that he did, in fact, have AML. Our life changed forever.

On Monday morning, Joe and Heather Mangano (AJ's high school football coach and his wife) came to the hospital. They brought us this "PlayBook." I was unsure at the time how or why I would ever use it...I think I was still in MAJOR denial that anything could possibly be wrong with AJ.

As the doctors proceeded with his treatment, there were so many new things I had to learn, all medical jargon, timelines, symptoms to watch for, etc. Then, I had to be able to remember it all to be able to tell my husband, who was home with our other son. AJ's body seemed to react so differently than even the doctors expected. He had so many reactions to so many things, they began to call him, "Mr. 1%" (the medications tend to say that less than 1% of the patients will have this reaction). I began to use the PlayBook in earnest! I wrote down everything. This allowed me to be part of the discussions with the doctors. This finally gave me some power. This finally gave me some control! I was the one with him 24/7. I was his advocate...I was his MOM! The doctors began referring to the PlayBook as we discussed his care. I became part of the team.

In February, we finally left the hospital at UVA. We began our journey, first to Johns Hopkins then finally to St Jude Children's Research Hospital. With every move, we took along our PlayBook. We were able to reference it and use it in all our discussions with the doctors. It grew over our 14 month journey. Actually it became the size of 4 large binders. But I was our "GO TO"... It was that only piece of this crazy journey we had any control over. And, when you're the Mom and all you can do is sit back and watch, it gives you just something...something you CAN have control over.

Laura Slye
~ Mom/Caregiver



Testimonials

“Thinking about you. In fact I think of you every day when I look down at your notebook. People have offered to help by running errands, preparing food but this bar far is the most useful tool we have. THIS was so very tangible. THIS gave me a little bit of control in a chaotic crisis. Thank you for turning your very difficult journey into something that helped someone else so much!”

Beth Blauer, Baltimore, MD
(Husband stage 4 lung cancer)



Medications

Prescription Name:	Strength: <input style="width: 90%;" type="text"/>
Prescription #:	
For:	
Dosage: (X p/Day) <input style="width: 60px;" type="text"/>	# Refills: <input style="width: 60px;" type="text"/>
Doctor:	Date: <input style="width: 60px;" type="text"/>
	Cost: \$ <input style="width: 60px;" type="text"/>
	Pharmacy: <input style="width: 90%;" type="text"/>
With food: <input style="width: 60px;" type="text"/>	Prior to Eating: <input style="width: 60px;" type="text"/>
	AM <input style="width: 60px;" type="text"/>
PM <input style="width: 60px;" type="text"/>	Before Bed: <input style="width: 60px;" type="text"/>
	Other <input style="width: 60px;" type="text"/>
Possible Side Effects: (nausea, loss of appetite, headache, diarrhea, etc.)	
<hr/>	
Drug Interactions:	
<hr/>	

Prescription Name:	Strength: <input style="width: 90%;" type="text"/>
Prescription #:	
For:	
Dosage: (X p/Day) <input style="width: 60px;" type="text"/>	# Refills: <input style="width: 60px;" type="text"/>
Doctor:	Date: <input style="width: 60px;" type="text"/>
	Cost: \$ <input style="width: 60px;" type="text"/>
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PM <input style="width: 60px;" type="text"/>	Before Bed: <input style="width: 60px;" type="text"/>
	Other <input style="width: 60px;" type="text"/>
Possible Side Effects: (nausea, loss of appetite, headache, diarrhea, etc.)	
<hr/>	
Drug Interactions:	
<hr/>	



Medical History

Your Full Name: _____ **Address:** _____

City, St, ZIP _____

Telephone: _____ email: _____

Primary Care Physician: _____

Address: _____ City, St, ZIP _____

Telephone: _____ email: _____

Existing Conditions:

Type: _____	Treatment: _____
From: _____	To: _____
Medications: _____	Medications: _____
Treated by: _____	Tel #: _____
Type: _____	Treatment: _____
From: _____	To: _____
Medications: _____	Medications: _____
Treated by: _____	Tel #: _____
Type: _____	Treatment: _____
From: _____	To: _____
Medications: _____	Medications: _____
Treated by: _____	Tel #: _____

Previous Surgeries, Diseases, Hospital Stays or Allergic To:

1 _____

2 _____

3 _____

4 _____



Emergency Room Treatment

Hospital:	_____	Date:	_____	Time:	_____
Symptoms: (Be Specific)	_____ _____ _____				
(Pain Level 1-10)	_____ _____				
Diagnosis:	_____ _____ _____				
ER Treatments:	_____ _____ _____ _____ _____				
Hosp. Admittance:	Date: _____	Time: _____	Room #:	_____	
ER Treatment:	Physician _____ Speciality: _____				
	Physician Asst: _____ Speciality: _____				
	Nurse: _____ Speciality: _____				
Tests/Treatments	_____ _____ _____ _____				



Appointments / Consults

Doctor:

Physian Asst			
Date:	Day:	Time:	
Address:			Suite #:
	City:	State:	ZIP:
Office Tel:	email:		

Items Discussed: (Details are important)	1) _____
	2) _____
	3) _____

Present Treatment: (Review treatments, side effects & pain level 1 - 10 management)	_____

New Medications: (Review all medications prescribed for possible side effects & pain mgt.)	1) _____
	2) _____
	3) _____

New Protocols: (Treatments, schedules frequencies)	1) _____
	2) _____
	3) _____

Follow-up Questions: (If it's on your mind, ask it!)	1) _____
	2) _____
	3) _____



Medical Contact Information

Primary Physician: _____ **Speciality:** _____

Physician Asst: _____

Address: _____ **City, St, ZIP** _____

Phone# : _____ **Fax:** _____

email: _____

Oncologist: _____

Physician Asst: _____

Address: _____ **City, St, Zip** _____

Phone# : _____ **Fax:** _____

email: _____

Radiologist: _____

Physician Asst: _____

Address: _____ **City, St, Zip** _____

Phone# : _____ **Fax:** _____

email: _____

Internist/Other: _____

Physician Asst: _____

Address: _____ **City, St, Zip** _____

Phone# : _____ **Fax:** _____

email: _____

Surgeon: _____

Physician Asst: _____

Address: _____ **City, St, Zip** _____

Phone# : _____ **Fax:** _____

email: _____

Hospital: _____

Address: _____ **City, St, Zip** _____

Phone# : _____ **Fax:** _____

Pharmacy: _____

Pharmacist: _____

Address: _____ **City, St, Zip** _____

Phone# : _____

email: _____



Notification List

Emergency Contact:

Name: _____
Phone # : _____ Work #: _____
email: _____

<u>Family Names:</u>	<u>Tel #</u>	<u>email address</u>
1) _____	_____	_____
2) _____	_____	_____
3) _____	_____	_____
4) _____	_____	_____

<u>Work Names</u>	<u>Tel #</u>	<u>email address</u>
1) _____	_____	_____
2) _____	_____	_____
3) _____	_____	_____
4) _____	_____	_____

<u>Friends</u>	<u>Tel #</u>	<u>email address</u>
1) _____	_____	_____
2) _____	_____	_____
3) _____	_____	_____
4) _____	_____	_____



Insurance

Primary Carrier:	_____	Policy #:	_____
Address:	_____		
	City:	State:	ZIP:
	_____	_____	_____
Phone #:	_____	Fax #:	_____
Contact Name:	_____		
	email:	_____	

Supplemental Carrier:	_____	Policy #:	_____
Address:	_____		
	City:	State:	ZIP:
	_____	_____	_____
Phone #:	_____	Fax #:	_____
Contact Name:	_____		
	email:	_____	

Medicare:	_____	Policy #:	_____
Contact Address:	_____		
	City:	State	ZIP:
	_____	_____	_____
Phone #:	_____	Fax #:	_____
Contact Name:	_____		
	email:	_____	

Cancer Insurance:	_____	Policy #:	_____
Address:	_____		
	City:	State:	ZIP:
	_____	_____	_____
Phone #:	_____	Fax #:	_____
Contact Name:	_____		
	email:	_____	



Insurance Requirements

Referrals Necessary:

MRI/CAT/PET Scans \$ _____ Doctor: _____

Hospitalization \$ _____ Doctor: _____

Blood Work \$ _____ Doctor: _____

Pre-Authorizations

Hospitals: Name: _____ Auth #: _____

Specialists: Name: _____ Auth #: _____

Treatments: Name: _____ Auth #: _____

Co-pays:

Prescriptions: \$ _____

Dr. Visits: \$ _____

Chemo/Radiation Treatments: \$ _____

Hospitalization \$ _____

Additional Requirements

Notes



Home / Hospice Care

Company:							
Type:	Nursing:		Hospice:		Daycare:		Equip:
	Therapists		Cleaning		AM		PM
Address:							Suite #:
	City:			State:		ZIP:	
Phone #:				Fax #:			
Contact:				email:			
Cost:	\$		Return By		Ins. Pay?		
Names:			Cell #			eMail	
Equipment:				Cost:			

Company:							
Type:	Nursing:		Hospice:		Daycare:		Equip:
	Therapists		Cleaning		AM		PM
Address:							Suite #:
	City:			State:		ZIP:	
Phone #:				Fax #:			
Contact:				email:			
Cost:	\$		Return By		Ins. Pay?		
Names:			Cell #			eMail:	
Equipment:				Cost:			

