

MANAGING YOUR MEDICAL TEAM

A PATIENT'S PERSPECTIVE

OBJECTIVES

- To help you create and maintain maximum control over how you interact with your medical team**
- To help you record/maintain medical records**
- To share best practices (interactive session!)**



WHO'S ON YOUR TEAM?

Family Practice
Rheumatologist
Urologist
Therapists:
 Physical
 Occupational
 Speech



Gastroenterologist
Cardiologist
Neurologist
Labs
Pharmacies
Centers
Who Else???

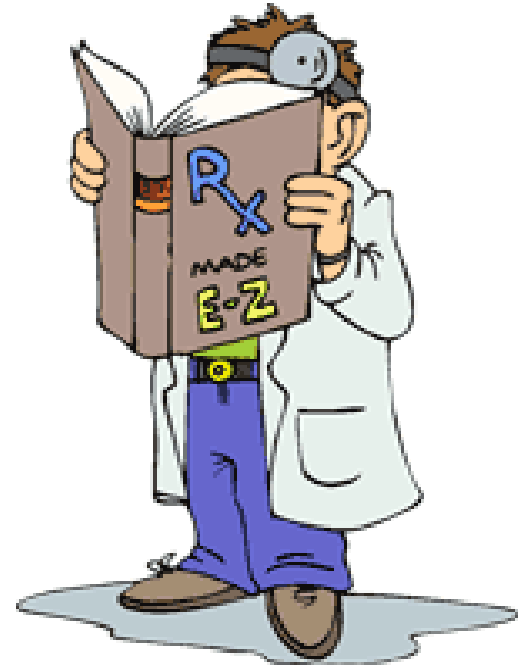
...”SPECIAL” SPECIALISTS?

Johns Hopkins Myositis Center

Mayo Clinics

University of XXX

Others



HOW TO GAIN/KEEP CONTROL....

Doctors?

Appointments

Collaboration

Records?

Electronic

Paper

Doctors' office portals



DOCTORS & APPOINTMENTS

APPOINTMENT PREPARATION

Do your part!

Take with you:

Current situation or Questions

Other results; docs/therapists/labs

Planner/calendar/phone

A 'buddy'

Be on time! (KNOW when it is)



'BUDDY' GROUND RULES

Who talks and when?

Who takes notes or records?

What if doctor talks to buddy, not you?



APPOINTMENT – DURING

Watch the chit-chat

Start with what you brought

- >Current situation (next slide) OR...
- >Question sheet - multiple copies can help (following slide)
- >Input from labs/tests/other doctors' notes

Introduce your buddy



APPOINTMENT – DURING

Current situation: brief, objective summary

Remember to include dates!


Marianne Moyer – Current Situation – July 2017

1. After 4 Rituxan infusions (9-14, 1-16, 1-17, 5-17) I see no change in my strength.
2. From June '16 to June '17 I reduced prednisone from 11 to 7 mg daily.
3. I continue to receive 50 grams IVIG for 2 days, every 4 weeks.

APPOINTMENT – DURING

Especially when diagnosis is new, you have many questions. Limit them.

Marianne Moyer - QUESTIONS for Dr. Wonderful, July, 2017

1. Is Rituxan working?
 2. Infusions more or less often?
 3. Can I reduce prednisone?
 4. Change IVIG infusions?
- 

APPOINTMENT – CLOSING

Review notes taken

Is important info clear?

Medication changes

Referrals

What will doc “e-send”?

Do you or buddy have other questions?



APPOINTMENT CLOSING (CONT'D)

Will doctor record visit in notes?

Get before you leave?


Get via Portal?

Copies to other doctors?

Next appointment? (Did you bring calendar?)



BETWEEN APPOINTMENTS

- Update your records (more to follow)
 - Go to doctor's portal for notes
 - Most common Portal software is Epic; "MyChart" to patient
 - Can your docs access others' portals?
 - Do what you were told to do!
- 

WHAT TO DO WHEN DOCTORS DON'T TALK

Is it a tug of war or do they “play nice”?

You could ask Doc A to contact Doc B

OR do all the info transfer yourself

OR fire the doc who won't cooperate (hard).

OR just fume and do nothing (harder).

Guess why that's not a good thing?



RECORD KEEPING

LET'S TALK 'OPTIONS'

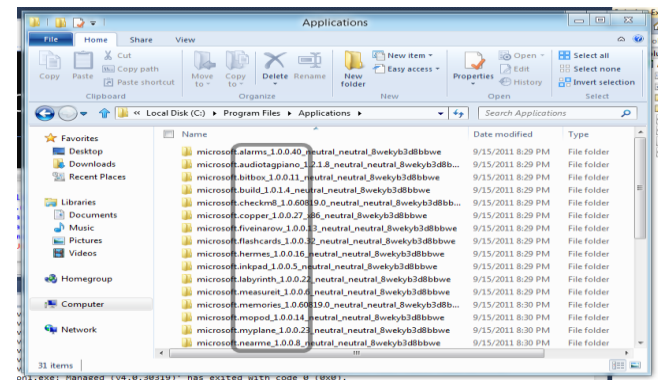
What makes YOU comfortable?

What do you *use*?

Is it time to reconsider?



OR



THERE'S AN 'APP' FOR THAT!

Techno-phobes...me?

I-Phone Health App:

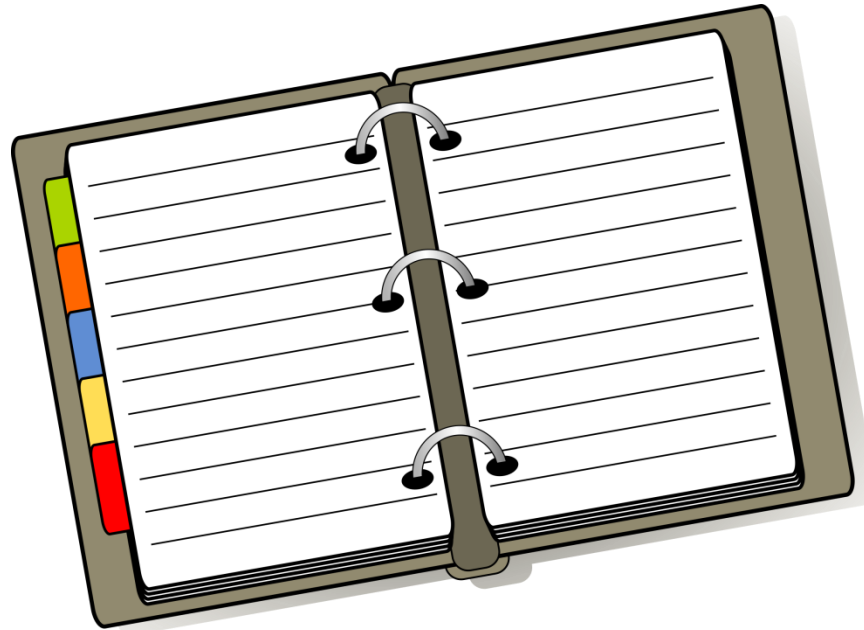
- BP, A1C, Steps and more

Droid; several apps

- Link to My Chart
- Track visits, CPK, meds, etc!



GOOD OLD THREE-RING BINDER WITH TABS!



SUGGESTED BINDER TABS

Index

Filed chronologically (most recent on top)

- Medications
- Test results (blood, EMG, CT, MRI, etc.)
- Notes from doctors' visits (by specialty)
- Events log
- Optional sections: expenses, tax issues,
- Medical journal articles, warranties, etc.
- What else?

WHY DO I NEED THIS?

For your current Medical Team

Not a bad idea to take with you to appointments

For a future Medical Team Member

When you see a new doctor or...

New 'challenges' pop up

Imagine you fell and went to the ER...



SOMETHING PORTABLE?



shutterstock - 259143614

I CARRY . . .

Prescriptions		Reason Taken	Prescribing Dr.	Notes
Medication	Dosage			
Hydrocodone/chlorphen ER suspension	1 tsp 2x daily	Cough	Seeman	30-day supply from Walgreen's
Levoxyl	75 mcg daily	Hypothyroid	Mardones	*
Losartan (Cozaar)	100 mg daily	Blood Pressure	Mardones	*
Norvasc (Amlodipine)	5 mg daily	Blood Pressure	Mardones	*
Prednisone	7 mg daily	Myositis	Crager	*Stopped reducing 6-1-17
Prilosec	40 mg daily	GERD	Roddenberry	OTC now
Zetia (Ezetimibe)	10mg daily	Cholesterol	Mardones	*
IVIG	50 gm 2 days/mo.	Crager	Infused at home	MedPro-Diplomat
Rituxan infusion – 6 months between	1000 mg infusion	Crger/Rosen	Infused at Rosen's	
Benzonatate (Tessalon Pearls)	200 mg daily	To help sleep	Seeman	*
Symbicort Inhaler	80.5, 2x daily	Breathing	Glassberg	*
Over-the-counter medications				
Medication	Dosage			
Flaxseed oil	600 mg twice daily	Cholesterol		
Multivitamin	daily	Gen'l Health		
Vitamin D3/Calcium	1000/1480 mg daily	Bone health		Get Dexa in odd years, April
Vitamin C	2000 mg twice daily	Gen'l Health		
Delsym 12 hour cough syrup	10 mg	To help sleep		
As Needed (PRN) Prescriptions				
Ambien (Zolpidem)	10 mg PRN	Sleep Aid	Crager	*Use after IVIG, also ~5x/month
Econazole	Applied PRN	Fungus, feet ++	Hopkins	*
				* Provided by Express Scripts

MY MEDICATIONS:

As of date:

Prescriptions:

Dosage, Schedule

OTC Meds:

Dosage, Schedule

PRN Meds:

Dosage, When/why you take it,

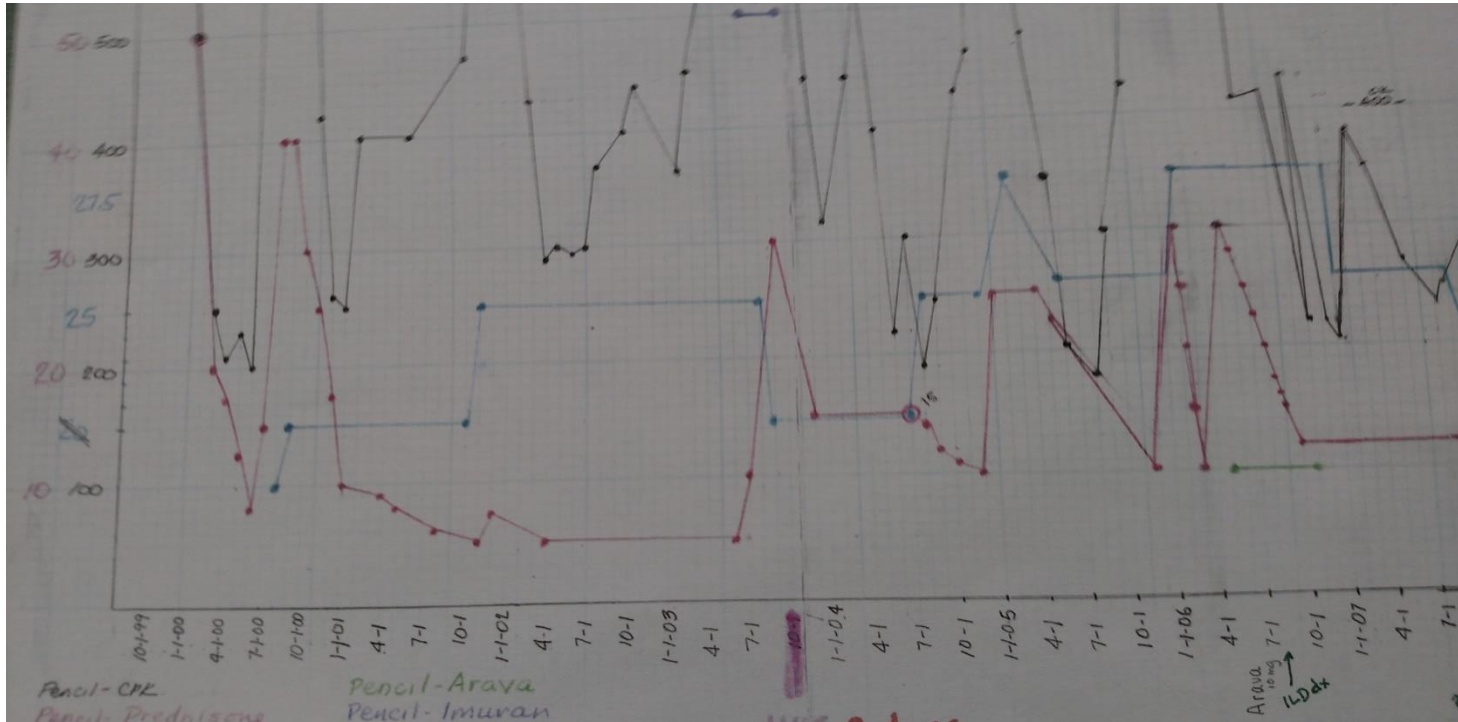
Could Include Meds no longer taken and why...



EVENT LOG

2016	
1-14	Rituxan infusion in Deerfield Beach
2-2	Sputum test at Pinnacle
2-3	CT of chest (Crager asked Seeman to do it)
2-3	Start daily Kerydin for toenail fungus
6-16	Began weekly wound therapy sessions on left leg, Manatee Hospital
8-16	Released from wound therapy.
11-15	Mammogram and ultrasound
11-21	Flu shot
2017	
4-27	Dexa
5-12	Chest CT (no change)
5-26	Walk test; could not complete from shortness of breath
6-1	PFT (no change)
6-6	UMiami Dr Glassberg & Dana. Scary DX for need for O2
6-14	Clinicare nurse at house to do walk test with O2 titrate
6-20	Overnight O2 test (I saw it at 97% almost continuously) (last one 2-17-14)

WHAT ABOUT THE 'MONSTER' CHART?



WHAT ELSE DO I NEED TO RECORD?

Medical Team Members

Name, specialty or title

Address all offices? Miles round trip?

E-mail/Portal contact; user name, password

Phone number, emergency, cell and fax

Office Hours

Your insurance ID and Group Numbers



FUTURE PLANNING

Wills

Power of Attorney

Medical Power of Attorney

Advanced Directive

Do your docs have copies?

Insurance Policies with current beneficiaries

Why include this?



...IT'S ALL PART OF YOU MANAGING YOUR WELL-BEING!



Thank You!

Marianne.Moyer@verizon.net