



MANAGING YOUR MEDICAL TEAM

A PATIENT'S PERSPECTIVE

OBJECTIVES

To suggest how myositis patients and caregivers can create and maintain the maximum possible control over how their medical team *treats* them

To help patients record and maintain their own medical records

To share best practices (interactive session!)



WHO'S ON YOUR TEAM?

Family Practice
Rheumatologist
Neurologist
Dermatologist
Therapists:
■ Physical
• Occupational
• Speech



Gastroenterologist
Cardiologist
Urologist
Pulmonologist
Who Else???

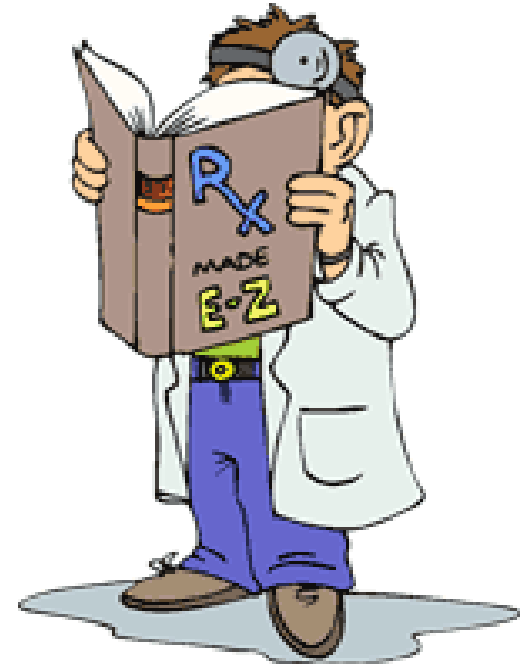
...”SPECIAL” SPECIALISTS?

Johns Hopkins Myositis Center

Mayo Clinics

University of XXX

Others



HOW TO CONTROL....

Doctors?

Appointments

Collaboration with other professionals

Records?

Electronic

Old-fashioned paper

Doctors' office portals



DOCTORS & APPOINTMENTS

APPOINTMENT PREPARATION

Get the most benefit every time:

Goal is to walk out KNOWING you “got” “it”

Preparation – do your part!

Take with you:

Current situation (verbal, paper or on screen)

Questions

Results of visits with other doctors/therapists/labs

A ‘buddy’ (if so, set ground rules)

Be early to be on time



'BUDDY' GROUND RULES

Who talks and when?

Who takes notes?

What if doctor talks to the buddy, and not you?

Roles may be difficult to establish and maintain.

Be flexible!



APPOINTMENT - DURING

Chit-chat takes up valuable time...

Start with what you brought

Current situation (next slide)

**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 of YOUR perception of situation. Remember to date everything!


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 2016 to June 2017 I reduced prednisone from 11 to 7 mg daily.**
 - 3. I continue to receive 50 grams IVIG for 2 days, every 4 weeks.**
 - 4. My CK has stayed in the normal range of <150 since January, 2016.**
 - 5. Because of factors like cancer surgeries, I get minimal exercise.**
- 

APPOINTMENT – DURING

Especially when diagnosis is new, you may have many questions. Try to limit them to the most important 5-7.

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

- 1. When/how do we know if Rituxan is working?**
 - 2. Should we reschedule infusions more or less frequently?**
 - 3. I want to continue reducing prednisone.**
 - 4. What factors will influence changing IVIG infusions?**
 - 5. Is there another medication to consider?**
 - 6. If so, how do we know if it works?**
- 

APPOINTMENT – CLOSING

Review notes taken

Is important info clear and will it be understandable later?

Should you record or take pictures of info like new med schedule?

Do you or buddy have other questions?

Will doctor record this visit in notes?

Can you have them before you leave?

Can you retrieve them via Portal?


How to get copies to other doctors?

Next appointment interval?

Express gratitude for their time and effort! They need to hear it!



BETWEEN APPOINTMENTS

- **Update your records (more on this to follow)**
 - **Go to doctor's portal for copy of notes**
 - **Most common Portal software is Epic which is "MyChart" to patient**
 - **Can all your docs access each others' portals?**
 - **Ask your docs which websites they recommend (like WebMD)**
 - **Do what you were told to do!**
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RECORD KEEPING

LET'S TALK 'OPTIONS'

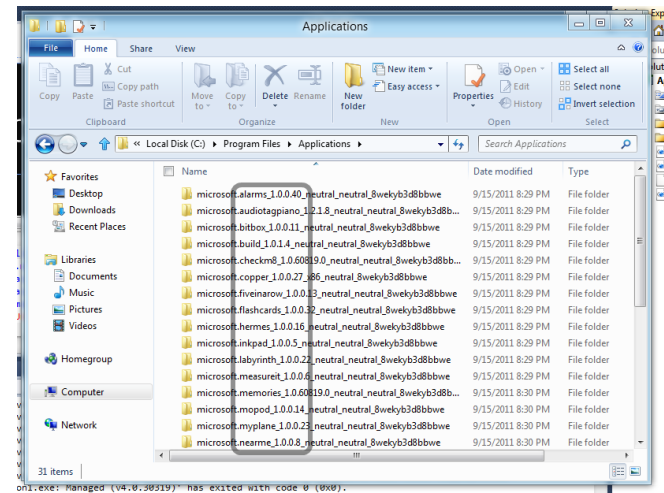
What makes YOU comfortable?

What will enable you to make them most use of what you have?

Is it time to ask for help?

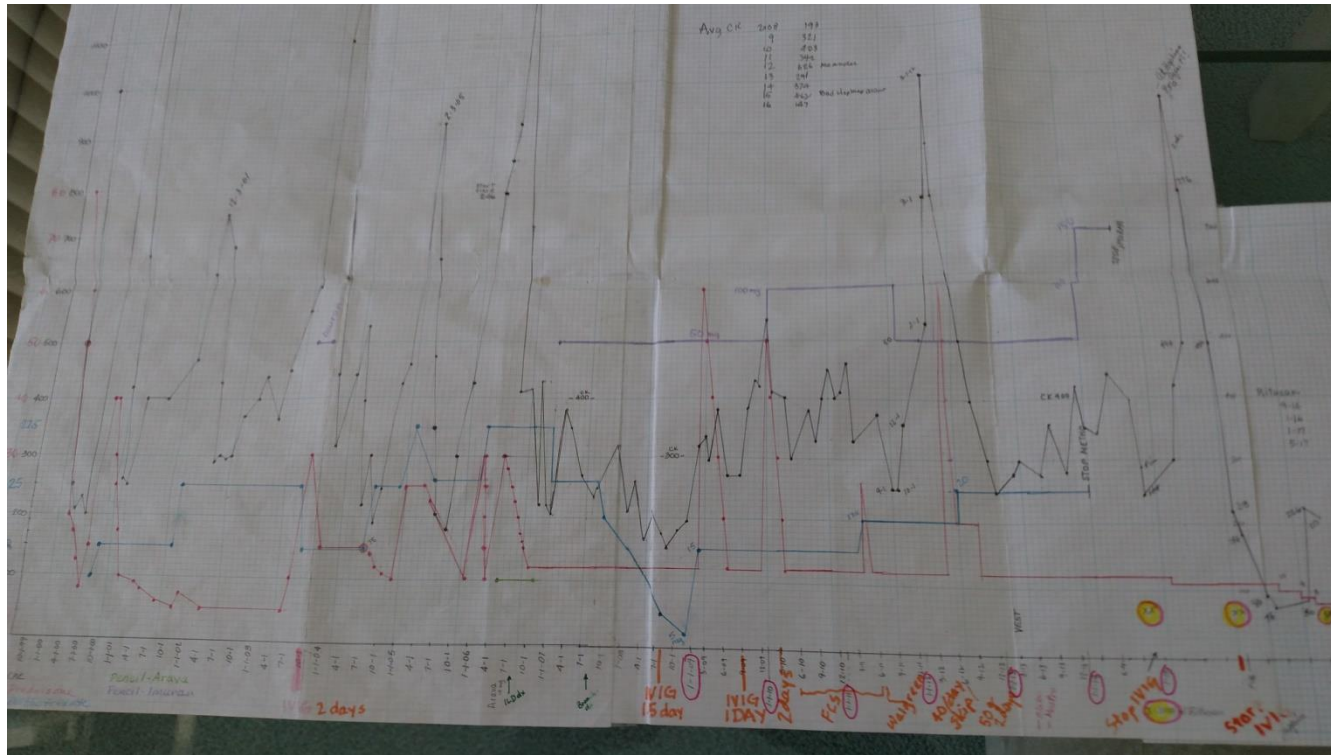


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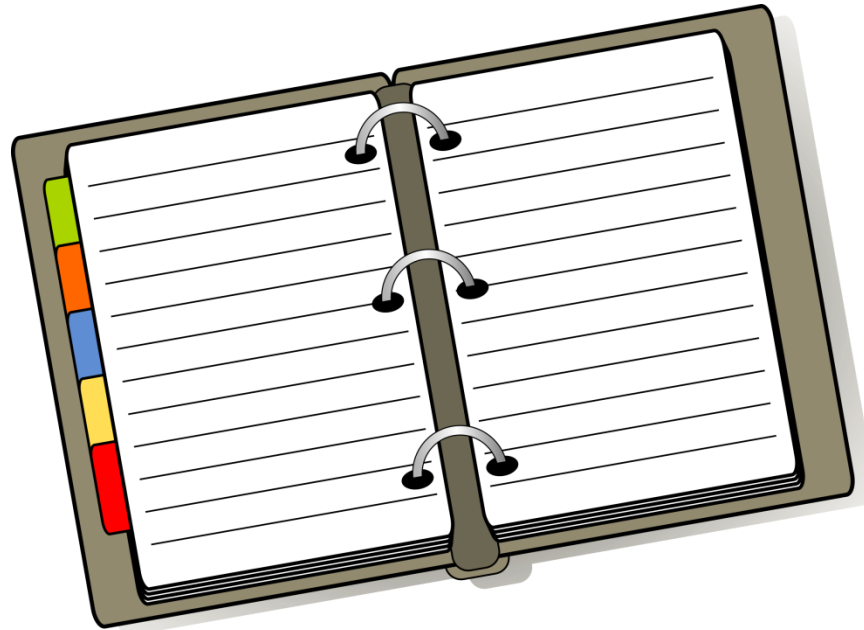


...OR THE REALLY 'OLD-FASHIONED' WAY?

(AND NO YOU CAN'T SEE THE DETAILS ON THIS)



GOOD OLD THREE-RING BINDER WITH TABS!



SUGGESTED BINDER TABS

Index

Tab contents filed chronologically (most recent on top)

- **Medications**
- **Test results (blood, EMG, CT, MRI, DEXA, biopsies, etc.)**
- **Notes from doctors' visits (by specialty)**
- **Optional sections: expenses, tax issues, etc.**
- **Medical journal articles**
- **Warranties on aids like walker, scooter, Hoyer lift, etc.**
- **What else?**

WHY DO I NEED THIS?

For your current Medical Team

Not a bad idea to take with you to all appointments

You may need to condense to most current or relevant records

For a future Medical Team Member

When you see a new doctor for whatever reason

(The old one moved, retired, or no longer accepts your insurance) (Or you fired him/her!)

New 'challenges' pop up...

**Imagine that you fell and had
to go to the ER....**



WHAT TO DO WHEN DOCTORS DON'T TALK

Have you ever felt like it's a tug of war?

How are you supposed to get everyone to 'play nice'?

Options start with you asking Doc A to contact Doc B.

OR You can do all the info transfers yourself.

OR You can fire the doc who won't cooperate (it's hard).

OR You can just fume and do nothing (harder).

Guess why that's not a good thing?



WHAT WE NEED TO CARRY AT ALL TIMES

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	Crager/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

YOUR MEDICATION RECORD MIGHT INCLUDE:

Prescriptions		Reason Taken	Prescribing Dr.	Notes
Medication	Dosage			
Over-the-counter medications		Reason Taken	Prescribing Dr.	Notes
Medication	Dosage			
As Needed (PRN) Prescriptions		Reason Taken	Prescribing Dr.	Notes
Medication	Dosage			

Schedule:	7am	9am meal	Noon meal	7pm meal	Bedtime



YOUR 'LOG' MIGHT INCLUDE

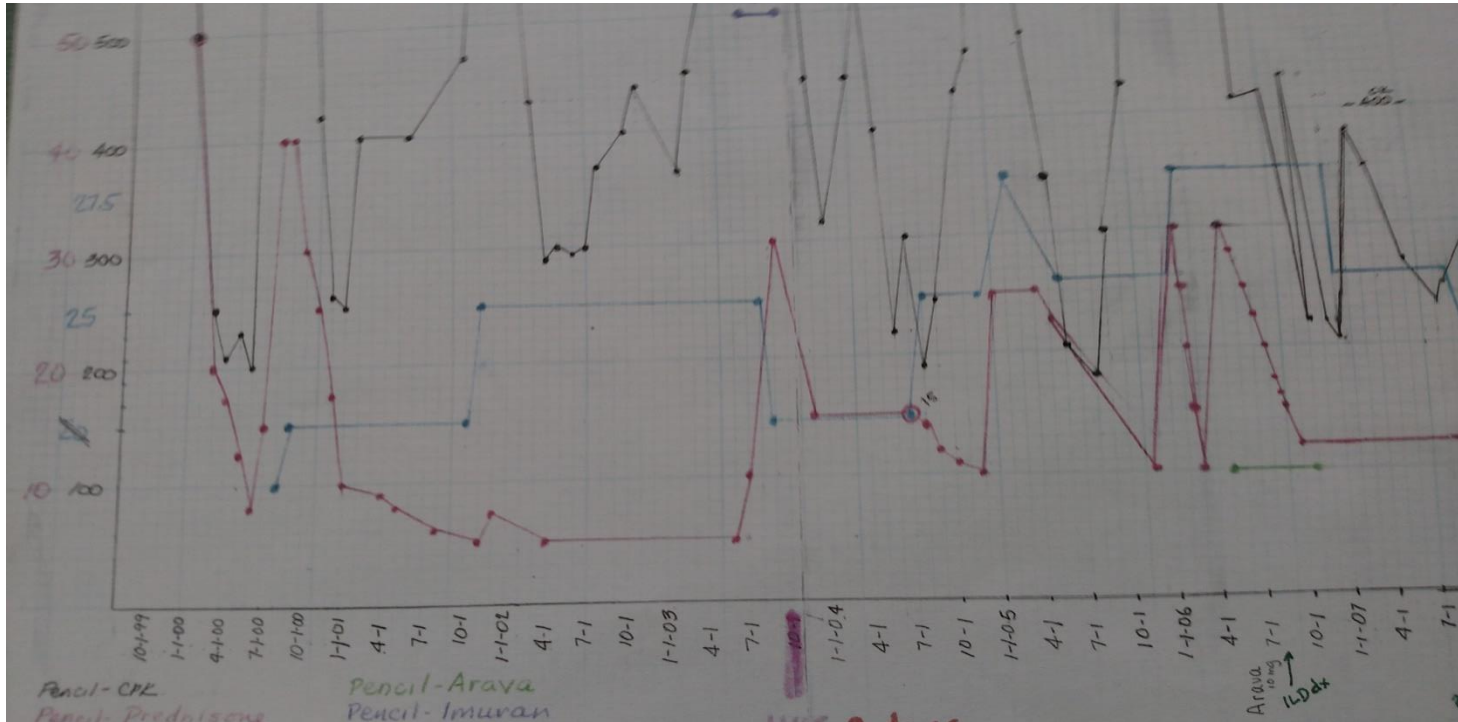
2016	
1-14	Rituxan infusion (4 hrs) in Deerfield Beach
2-2	Sputum test at Pinnacle
2-3	CT of chest (Crager asked Seeman to do it)
2-3	Start daily Kerydin for toenail fungus (used for one year-it helped but did not cure)
6-16	Began weekly wound therapy sessions on left leg, Manatee Hospital
8-16	Released from wound therapy. Huge scar, and dent in leg
11-15	Mammogram and ultrasound (some concern re discharge, right nipple-was ok)
11-21	Flu shot
2017	
4-27	Dexa
5-12	Chest CT (no real change)
5-26	Walk test; could not complete from shortness of breath
6-1	PFT (no real 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)

HERE'S ONE IN EXCEL

Date	Doctor/Clinic	Test	Condition, Change or Activity	Details/Notes
6/5/2008	Dr Smith, internist meds. Ordered CBC.		EKG	Appointment EKG normal, BP 120/80, no change in
6/6/2008			Hypertension	120/80
6/7/2008			Medication change	Increased prednisone to 20mg daily
6/9/2008	Dr Thomas, Gastroenterologist Retest in 1 year.		Endoscopy	Negative biopsy results.
7/15/2009			Muscle weakness	Continuing weakness in legs, core, and arms
7/20/2009	MJ Rehab Hospital weekly with Jeanie		Physical therapy	Start new sessions 3x
10/17/2010	Dr Jones, Rheumatologist labs: cpk = 65, sed = 4, potassium = 6.5.		Appointment	Continue on same meds, strength ok,
11/11/2011			Workout	30 mins walking, 30 mins light weights, stretching
12/2/2011	Test again in 3 months.		Blood tests	CMP, CBC, CPK. Normal ranges except cpk = 450.

WHAT ABOUT THE 'MONSTER' CHART?

(STILL CAN'T SEE DETAIL BUT...)



WHAT ELSE DO I NEED TO RECORD?

(AND HOW?)

Medical Team

Names and specialty or title like PA

Addresses (many have several offices)

E-mail or Portal contact and your user name and password

Phone number, emergency or cell and fax number

Office Hours (in Florida, offices close for 1.5 hours for lunch!)

Your insurance carriers with ID and Group Numbers

Why?

You tell me!



FUTURE PLANNING

Wills

Power of Attorney

Medical Power of Attorney

Advanced Directive

Do all your docs know about (have copies) of these?

Insurance Policies with up-to-date beneficiary information

Why include this?



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



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