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
Current situation: brief, objective summary

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.
APPONINTMENT – 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!
...OR THE REALLY ‘OLD-FASHIONED’ WAY?
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?
<table>
<thead>
<tr>
<th>Prescriptions</th>
<th>Reason Taken</th>
<th>Prescribing Dr.</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hydrocodone/chlorphen ER suspension</td>
<td>Cough</td>
<td>Seeman</td>
<td>30-day supply from Walgreen's</td>
</tr>
<tr>
<td>Levoxyl</td>
<td>Hypothyroid</td>
<td>Mardones</td>
<td>*</td>
</tr>
<tr>
<td>Losartan (Cozaar)</td>
<td>Blood Pressure</td>
<td>Mardones</td>
<td>*</td>
</tr>
<tr>
<td>Norvasc (Amlodipine)</td>
<td>Blood Pressure</td>
<td>Mardones</td>
<td>*</td>
</tr>
<tr>
<td>Prednisone</td>
<td>Myositis</td>
<td>Crager</td>
<td>*Stopped reducing 6-1-17</td>
</tr>
<tr>
<td>Prilosec</td>
<td>GERD</td>
<td>Roddenberry</td>
<td>OTC now</td>
</tr>
<tr>
<td>Zetia (Ezetimibe)</td>
<td>Cholesterol</td>
<td>Mardones</td>
<td>*</td>
</tr>
<tr>
<td>IVIG</td>
<td>Infused at home</td>
<td>MedPro-Diplomat</td>
<td></td>
</tr>
<tr>
<td>Rituxan infusion – 6 months between</td>
<td>Crager/Rosen</td>
<td>Infused at Rosen's</td>
<td></td>
</tr>
<tr>
<td>Benzonatate (Tessalon Pearls)</td>
<td>To help sleep</td>
<td>Seeman</td>
<td>*</td>
</tr>
<tr>
<td>Symbicort Inhaler</td>
<td>Breathing</td>
<td>Glassberg</td>
<td>*</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Over-the-counter medications</th>
<th>Medication</th>
<th>Dosage</th>
<th>Reason Taken</th>
<th>Prescribing Dr.</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flaxseed oil</td>
<td>600 mg twice daily</td>
<td>Cholesterol</td>
<td>Gen'l Health</td>
<td>Get Dexa in odd years, April</td>
<td></td>
</tr>
<tr>
<td>Multivitamin</td>
<td>daily</td>
<td>Gen'l Health</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vitamin D3/Calcium</td>
<td>1000/1480 mg daily</td>
<td>Bone health</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vitamin C</td>
<td>2000 mg twice daily</td>
<td>Gen'l Health</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Delsym 12 hour cough syrup</td>
<td>10 mg</td>
<td>To help sleep</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>As Needed (PRN) Prescriptions</th>
<th>Medication</th>
<th>Dosage</th>
<th>Reason Taken</th>
<th>Prescribing Dr.</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ambien (Zolpidem)</td>
<td>10 mg PRN</td>
<td>Sleep Aid</td>
<td>Crager</td>
<td>*Use after IVIG, also ~5x/month</td>
<td></td>
</tr>
<tr>
<td>Econozole</td>
<td>Applied PRN</td>
<td>Fungus, feet ++</td>
<td>Hopkins</td>
<td>*</td>
<td></td>
</tr>
</tbody>
</table>

* 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

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

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