Supplement 2 – Examples of Pre-Session Outlines

These outlines are prepared by the series organizer before each session and sent to both the participating faculty and participating patient for review. The faculty and patient then provide feedback to refine objectives and change, add, or omit questions as necessary. During the session, it is common that a few questions are skipped to ensure we remain on time. We purposefully “over-plan” so that patients can adequately prepare for any topics that might arise during the discussion.

Three sample session outlines are included below. Of note, minor changes to each outline have been made to preserve the confidentiality of our faculty and patients.

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**SAMPLE OUTLINE ONE**

**Outline for Multiple Sclerosis Patient Conference:**

This session featured a neurologist who specializes in multiple sclerosis and a patient with relapsing-remitting multiple sclerosis who had been on 3+ disease modifying therapies over a 15-year disease course.

* **Initial Case Presentation (12:05-12:20)**
	+ Faculty member will briefly introduce the patient, but then immediately allow patient to describe first symptom.
		- *Please spend only 2-3 minutes on this description and focus on symptoms only; do not disclose initial test results*
	+ **Questions for faculty:**
		- We heard about some sensory symptoms the patient was having before the development of optic neuritis. It can be hard to determine just how aggressive to be when working up these types of sensory symptoms. How helpful is the neurologic examination? Would a normal exam “exclude” MS? Are there any exam findings that would significantly increase the likelihood?
			* *Teaching points:* when to consider MS as a diagnosis
		- Tell us the initial examination findings?
			* Faculty will also outline initial work-up done and show a representative image from initial brain MRI
	+ **Questions for patient:**
		- What do you remember about first being told the diagnosis? At what point was it clear to you that you had MS?
		- Can you think of any specific things that doctors did or said to you during these initial conversations that was especially helpful? Anything they should have avoided?
		- What do you think is most important for doctors to convey during an initial discussion about this diagnosis?
	+ **Questions for faculty:**
		- Do you have any advice for providing an initial MS diagnosis?
* **Selecting initial disease modifying therapy (DMT) (12:20-12:35)**
	+ **Faculty** will begin by providing 2-3 slides to serve as a framework for residents:
		- Timeline of MS drug landscape
		- How can we organize the ~20 MS drugs in our mind in a way to help with initial decision making
	+ **Question for faculty:**
		- When you are making an initial MS diagnosis, do you always start a DMT? Under which circumstances might you first observe?
		- Is there a one-size fits all first-line medication that you turn to? If not, what factors do you use to determine which medication to recommend?
			* (One slide here could be helpful for bullet points, e.g. Severity of MS, age, co-morbidities, route, etc)
	+ **Question for patient:**
		- What was the first medication you started for MS? Were you given any choice in the matter? What do you remember being told about this medication?
	+ **Question for faculty:**
		- How do you typically involve the patient in this decision? For example, do you always give patients multiple options to choose from, or just give your one personalized recommendation?
			* How much does your strategy depend on the specific patient?
			* Do you ask patients about how much choice they want?
	+ **Question for patient:**
		- You were diagnosed at a very young age. What was it like suddenly having a medication to take on a routine basis?
			* In retrospect, are their things that could have been done to increase your chances of adherence?
* **Changing DMTs (12:35-12:45)**
	+ **Question for patient:**
		- How long were you on [first choice]? What made you switch?
	+ **Question for faculty:**
		- How do you know it is time to change medications? How long is required before you can determine if a medication is “working?”
			* (Consider a slide here)
	+ **Question for both**
		- Can you walk us through the various DMT changes you have had over the years?
	+ **Question for faculty:**
		- When you start a patient on natalizumab or B-cell depleting therapy, how do you discuss the risk of PML? It can be hard to conceptualize such a low probability yet high consequence event.
	+ **Question for patient:**
		- How did you prioritize risk of PML?
* **Symptom Management for MS (12:45-12:55)**
	+ **Question for patient:**
		- What has it been like to live with a chronic illness for the last 15 years? Can you give us some examples of how this affects you day to day?
		- What symptoms are most problematic day to day? Can you give us some examples of useful interventions that have been done to help?
	+ **Question for faculty:**
		- What symptoms do you screen for regularly in patients with MS?
		- Can you tell us how you manage fatigue and depression in your patients?
* **Questions from Residents/Audience (12:55-1:00)**

**SAMPLE OUTLINE TWO**

**Outline for Functional Neurologic Disorder (FND) Patient Conference**

This session featured a general neurologist who specializes in the care of patients with FND and a patient who developed FND after an accident, causing both weakness and abnormal movements.

**Initial Case Presentation (12:05-12:15)**

* **Questions for patient:**
	+ I understand that your symptoms began after you had an accident. Could you tell us what you remember about that accident and what happened in the few days afterwards?
	+ Your PCP diagnosed you with a concussion. You then saw a few other specialists in the next month or so. Could you tell us about your experience seeing those doctors? Did they agree that you had a concussion, and what did they tell you about what to expect?
	+ Most patients with concussion have gradual improvement of symptoms over several weeks. Was that your experience?
* **Questions for faculty:**
	+ Could you briefly describe what you view as the key components of post-concussive syndrome?
	+ How do you advise patients after a concussion? Do you agree with the concept of “brain rest?”
	+ How long is “too long” to recover after a concussion?

**Making a Diagnosis of FND (12:15-12:35)**

* **Questions for patient**
	+ About two months after your accident, your symptoms began to change. Could you tell us about those?
	+ What did you think was going on?
	+ After the symptoms developed, you were referred to see a neurologist. You then received a brain MRI and an EMG test. After you had those tests, you were referred to see another neurologist. Could you tell us about your experience seeing so many different doctors? How did this influence your opinion about what was causing your symptoms?
	+ One month later, you developed additional symptoms that led you to be hospitalized. Could you tell us about that?
* **Questions for faculty**
	+ Is it your experience with FND that many patients end up seeing numerous doctors before reaching a diagnosis? Is there anything that can be done to avoid this?
* **Questions for patient**
	+ When was the diagnosis of FND first suggested to you? What do you remember about that conversation and what was your reaction?
	+ Thinking back on it now, is there anything that could have been done differently to make the diagnostic process go more smoothly? Do you have tips for the residents in this regard?
* **Questions for faculty**
	+ Can you give some tips to the residents about how to make a “positive” diagnosis of FND, rather than taking a “rule-out” approach? How did you do this when you met [the patient].
		- (Show 1-2 slides about helpful historical or exam maneuvers to support an FND diagnosis)
	+ Can you also give some advice on how to deliver an FND diagnosis?
* **Question for patients:**
	+ Can you remember any concrete things that [the faculty member] did well? For example, anything that that was said that helped you understand what a functional neurologic disorder is?

**Treatment Course (12:35-12:55)**

* **Questions for faculty:**
	+ What treatment did you recommend?
	+ Is the treatment of every functional disorder the same?
		- (Show 1-2 slides on treatment paradigm for FND, and resources for residents to use when guiding treatment for FND patients)
* **Questions for patient:**
	+ Tell us about your experience going through treatment?
	+ What do you think had the biggest impact toward making you better?
	+ When could you start to tell that you were getting better?
* **Questions for faculty:**
	+ What do you do when patients are not getting better with the initial treatment?
	+ What do you do for patients who live far away, since many neurologists and physical therapists do not have experience treating FND?
* **Questions for patient:**
	+ Do you feel back to normal at this point? What do you expect going forward?
* **Questions from Residents/Audience (12:55-1:00)**

**SAMPLE OUTLINE THREE**

**Outline for Muscular Dystrophy Patient Conference:**

This session featured a neurologist who specializes in neuromuscular disorders and a patient with myofibrillar myopathy due to a de novo mutation in the desmin gene, resulting in both cardiomyopathy and skeletal myopathy.

* **Initial Case Presentation (12:05-12:15)**
	+ Faculty briefly introduces the patient’s clinical history, focusing on initial cardiac symptoms
		- *Would leave out that genetic testing was done, first just provide the biopsy results.*
	+ **Questions for faculty:**
		- Most residents are not very experienced with obtaining a muscle biopsy and what one can learn from them. How specific are the findings that were seen on this biopsy? Are they specific enough to provide a single etiologic diagnosis?
		- Is this situation typical? How often do we find sufficient etiologic diagnostic information on a biopsy?
		- *Teaching points (consider a slide):* biopsy vs genetic testing, how to sequence these
	+ **Questions for patient:**
		- Can you please talk to us about how your cardiologists talked to you about the biopsy result? How did they explain the result to you?
		- I understand they recommended following this up with genetic testing. How was this explained to you? Did you consider NOT doing genetic testing?
* **Results of genetic testing (12:15-12:25)**
	+ Faculty to show results of genetic testing – a novel mutation was found in a gene associated with muscular dystrophy
	+ **Question for faculty:**
		- At the time of this result, this was a novel mutation. How can we be sure that this is a pathogenic mutation and the actual cause of the problem? Is a biopsy always needed in such cases?
	+ **Question for faculty:**
		- Why is it important to establish a specific genetic cause if it is not treatable?
		- *Teaching points*: how predictable is progression, screening for cardiac or other complications, family implications
	+ **Question for patient:**
		- What do you remember about what you were told about the genetic diagnosis?
		- Did your doctors suggest that anyone else in your family should be tested? How did you approach this decision?
			* Depending on discussion and timing, may ask **faculty** to comment on how to advise patients about familial genetic testing
* **Approach to Skeletal Myopathy (12:25-12:35)**
	+ **Question for patient:**
		- You came to medical attention because of problems with your heart. When did it start to become clear to you that your skeletal muscles were affected by this problem?
		- **(Faculty** to provide examination findings on initial visit at this point)
	+ **Question for faculty:** A
		- re there things we can ask about on history that might be clues to a more long-standing skeletal myopathy? How do these clues help you determine whether a muscle disease might be an acquired or genetic process?
		- In this case, the cardiac involvement was the first clue that our patient had a muscle disease. The fact that cardiac muscle was involved can allow us to narrow down the etiologies we need to think about. What other features of the patient’s presentation do you use to help narrow down the diagnosis when you are considering muscle disease?
		- *Teaching points:* patterns of weakness, systemic features (e.g. rash, ILD), examination features (e.g. myotonia), respiratory involvement
			* (Show 1-3 slides summarizing your approach would be helpful - Keep in mind this doesn’t need to be a comprehensive lecture, goal is to just give the residents an initial framework they can refer to in future patients.)
* **How to treat an “untreatable” neuromuscular disease (12:35-12:45)**
	+ **Question for patient:**
		- Your doctors identified a genetic cause for your problems. Can you talk about what treating your disease means to you? (Would not talk about the treatments for the heart, since audience members are not cardiologists)
	+ **Question for faculty:**
		- What do you focus on during a follow-up with patients with genetic conditions such as this? What sorts of treatments do you offer to help quality of life?
		- *Teaching points (consider a slide)***:** Respiratory support, sleep apnea and its treatment, pain, orthotics and other gait aids for mobility and safety, home modifications, involving other specialists (PT, OT, SLP), screening for emerging complications
	+ **Question for patient:**
		- Can you show us any assistive devices or modifications to your home that have been particularly helpful in your day to day life?
* **Shared decision making about heart transplant (12:45-12:55)**
	+ **Faculty** to provide brief synopsis of relevant history to get us to the present day
	+ **Question for patient:**
		- When did your physicians start to talk to you about the option of considering a heart transplant? Had you had any experience or prior knowledge about organ transplantation?
	+ **Question for faculty:**
		- Can you talk to us about the necessary considerations when thinking about organ transplantation for a genetic disease? How did the skeletal myopathy play into the decision making?
	+ **Question for patient:**
		- Can you talk to the residents about how your doctors have framed this decision for you? What has been most useful and what has been not so useful?
* **Questions from Residents/Audience (12:55-1:00)**