

Living with Scleroderma

Education forum for those affected by scleroderma

Shared Decision Making and the Patient-Physician Partnership

Andrea Gardner, RN

Two Different Views

“Patients suffer illnesses, and physicians diagnose and treat their diseases”¹

- Physicians are experts in the normal and diseased states of the body
- Patients are experts in the experience of ill health

¹Cordier, J-F. “The Expert Patient: Towards a Novel Definition.” *European Respiratory Journal*. Oct 2014, (44.4) 853-857

Be a partner: Prepare and Participate

Prepare

One week before appointment

- What will my doctor want to know?
- Will my doctor have all the information to give opinions and recommendations?
- Request records, test results, notes from other doctors, etc.

Be a partner: Prepare and Participate

Prepare

Day before the appointment

- Symptom diary- Create/update/review
- List and prioritize questions
- Medication Reconciliation!

Create updated medication list and note any refill needs



Be a partner: Prepare and Participate

Participate

Admit

- Recommendations you have or have not been following
- Embarrassing symptoms

Ask

- Prioritized questions
- Pertinent questions



Be a partner: Prepare and Participate

Attention

- Take notes
- Summarize/clarify



Advocate

- Someone to help communicate your symptoms objectively to the doctor
- A friend/family member who understands your values and preferences can also help advocate for you.
- They can also help take notes and remind you of what the doctor said.

Partnering to Make Decisions

Shared decision making consists of health care providers and patients working together to make a health care decision that is best for the patient.



Shared Decision Making

Clearly define the problem and treatment options

- Discuss all possible options with your specialist
- Remember that not seeking treatment is a decision in itself
- In scleroderma, the options are often specific to each patient's needs

Shared Decision Making

Weigh the pros and cons of each option

- Consider relative importance of risks vs. benefits.
- Ask for concrete probabilities when possible
- How likely is it for these risks and benefits to happen?



Shared Decision Making

Clarify which option your healthcare provider recommends and why

- Doctors can't usually tell you which choice is best for you but they can explain why they are recommending certain options
- Ask for evidence-based information about available options

Make sure that you have enough support to carry out your decision

- Consider your resources: cost, childcare, travel, time off work, etc.
- Friends, family, and colleagues are important people to include in this decision

Summary

Prepare, participate and partner with your physician to make those tough decisions!