

# Palliative Rheumatology: Is it a thing?

---

# Agenda

1. Why did I become interested in Palliative Rheumatology?
2. What literature exists about Palliative Rheumatology?
3. How do I suggest approaching Rheumatologic symptoms as a Palliative Care provider?
4. How do I suggest approaching Rheumatologic medications as a Palliative Care Provider?

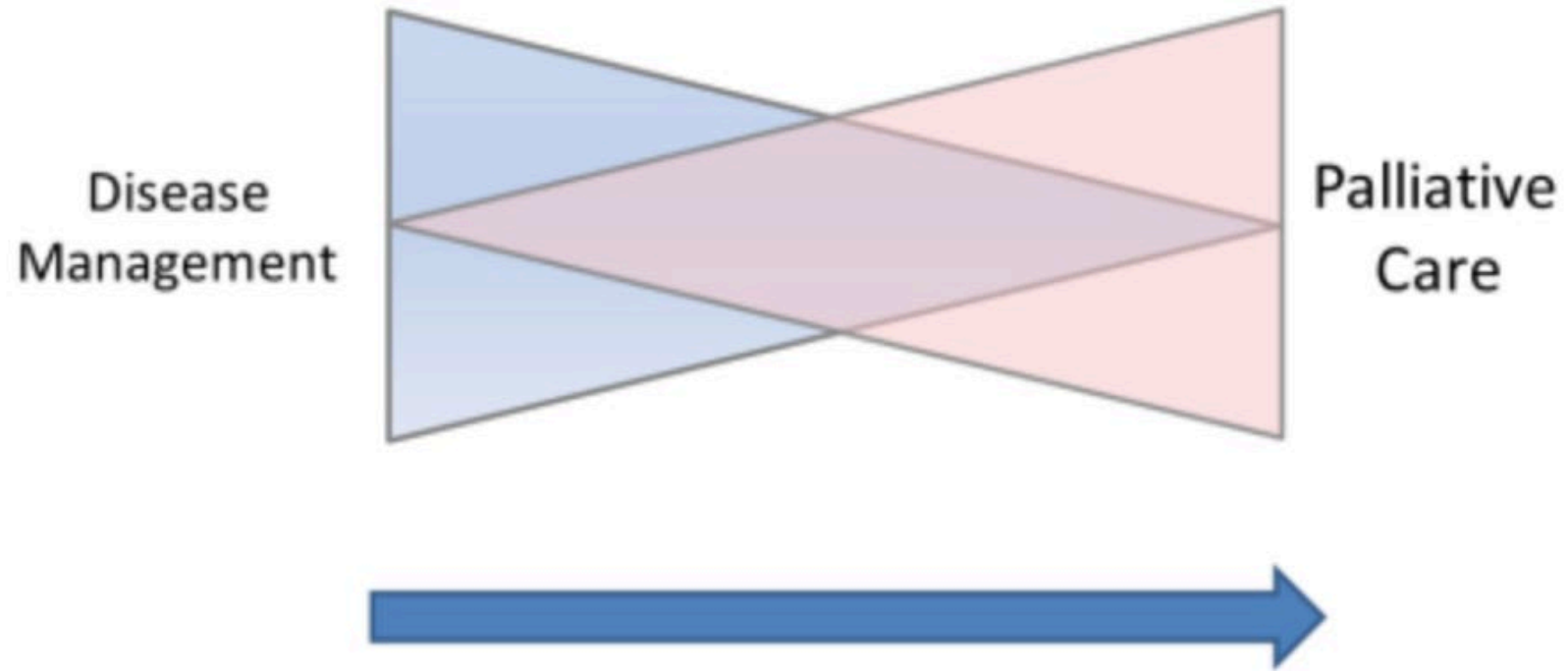
“My rheumatologist never asked what is important to me”

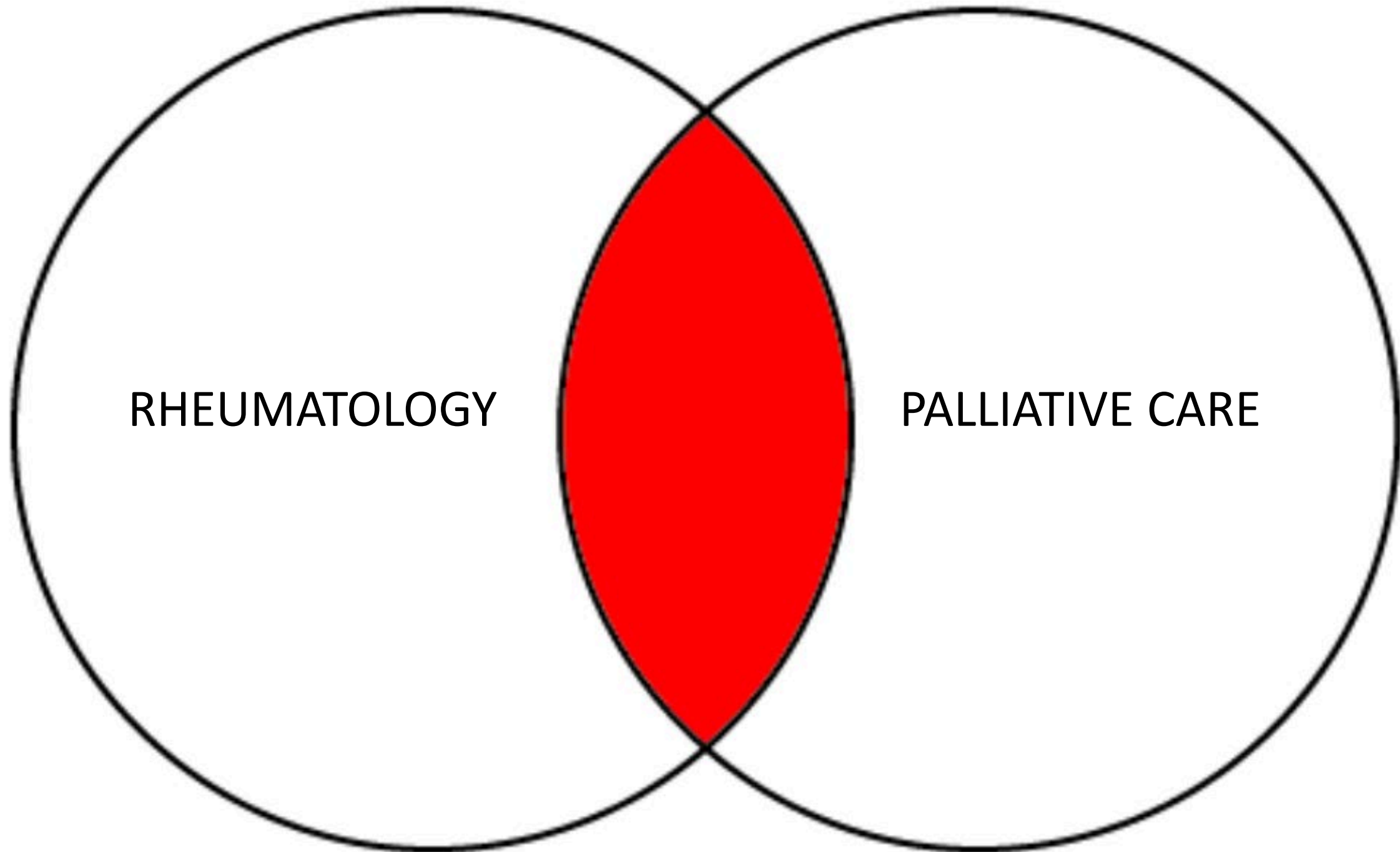
**ACTIVE (“CURATIVE”)  
TREATMENT**

**PALLIATIVE  
CARE**



WHAT'S THE MOST EFFECTIVE WAY TO REFRAME THIS?



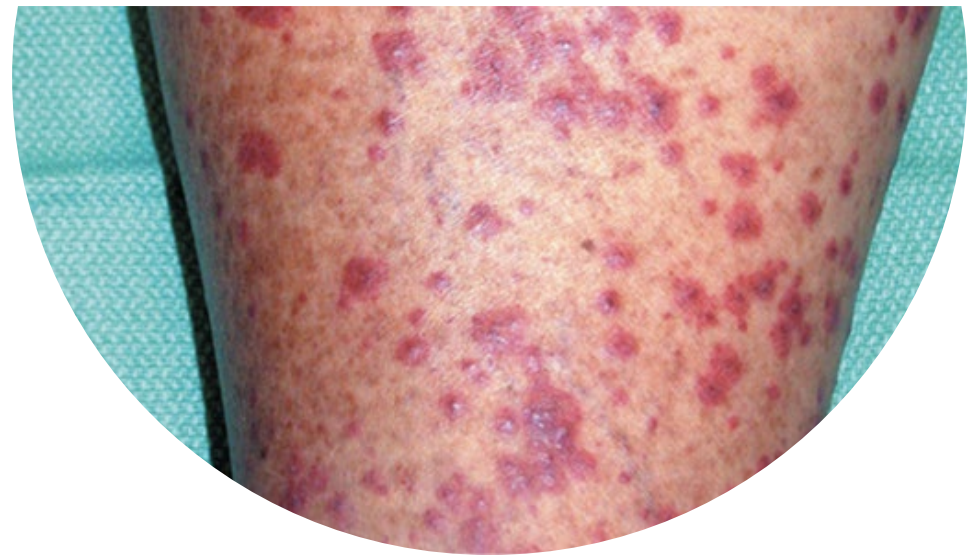
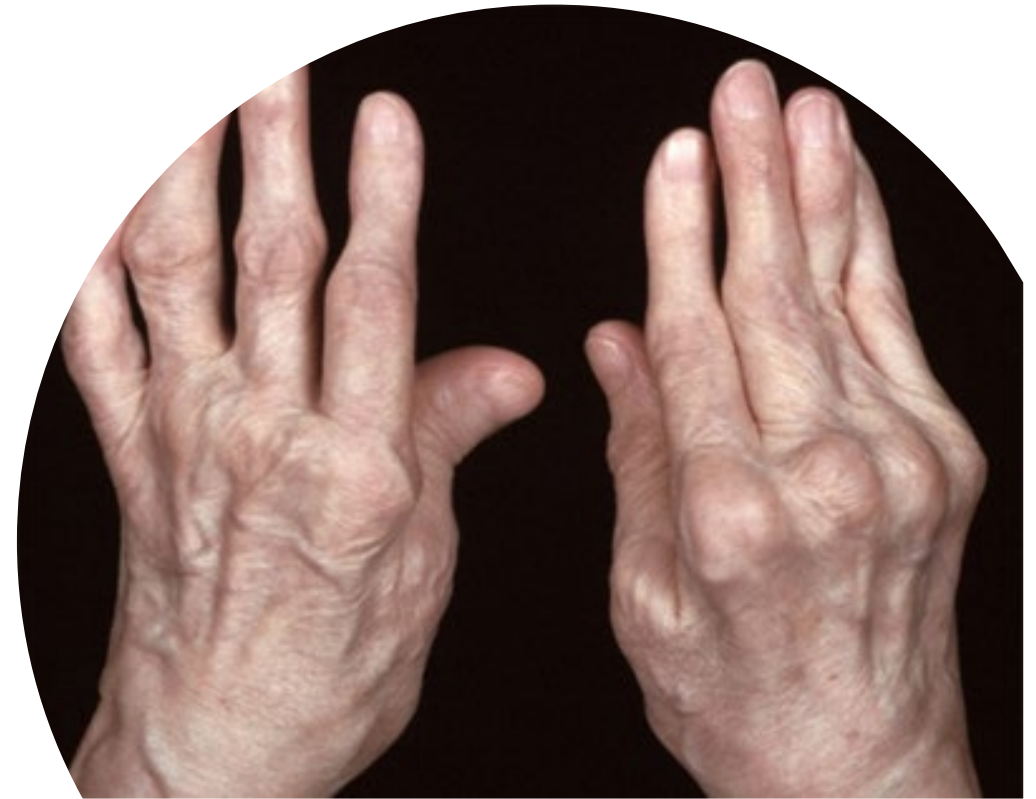


RHEUMATOLOGY

PALLIATIVE CARE

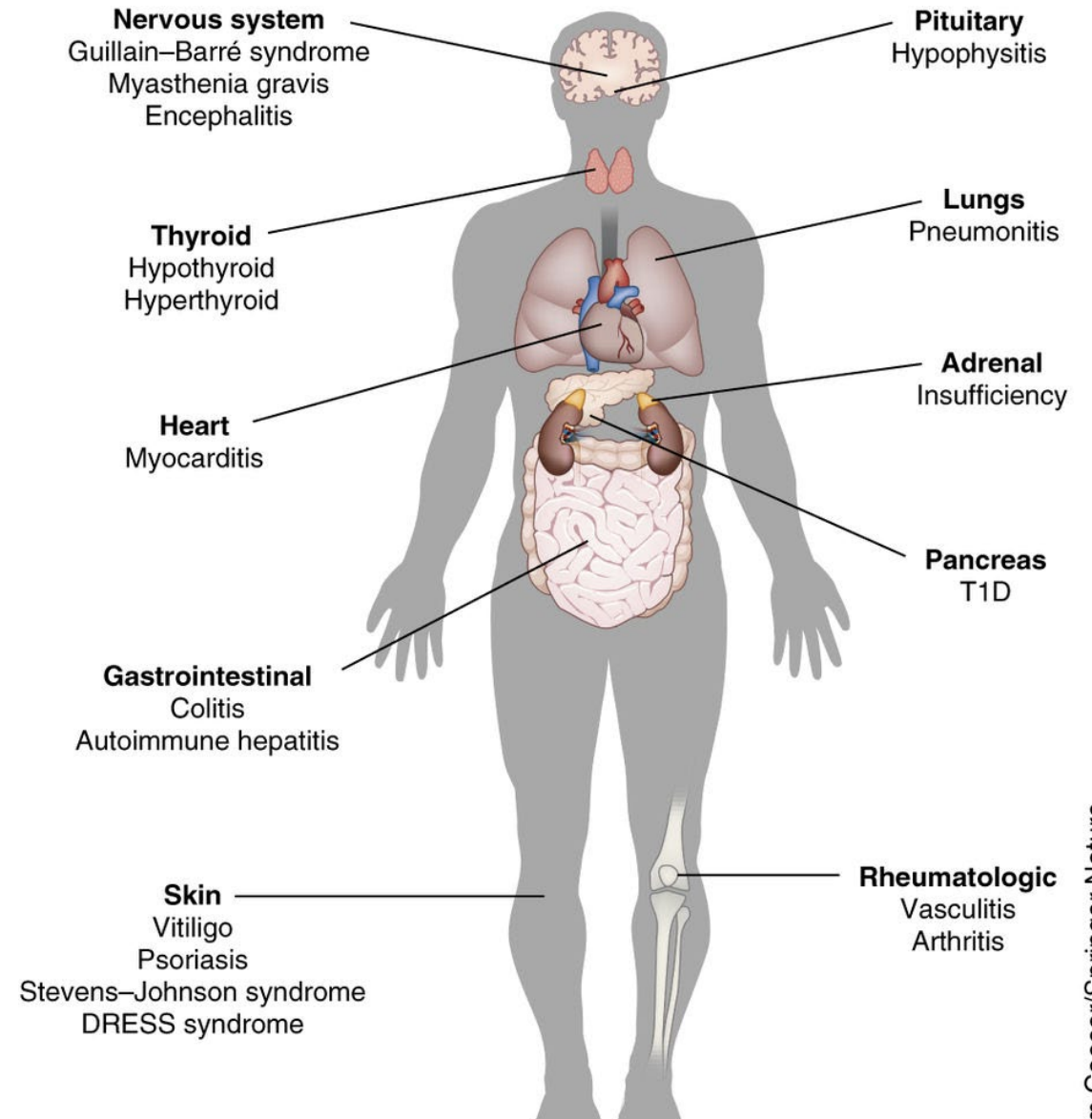
# The Landscape in Rheumatology

A patient population remains – those with **systemic vasculitis, systemic sclerosis, inflammatory myositis**, and severe courses of **systemic lupus erythematosus and inflammatory arthritis** – who still suffer from *life-limiting diseases* with *high symptom burden* and, often, *poor prognoses*.



# The Landscape in Rheumatology

- In addition, by “awakening the immune system,” new targeted therapies to treat metastatic cancer – namely, **immune checkpoint inhibitors** – have led to the development of *de novo* autoimmune diseases, so called ***rheumatic immune-related adverse events*** in > 30% of patients.
- This creates **another rheumatic population of patients with life-limiting diseases.**



# The Landscape in Rheumatology

- Rheumatologists are also skilled in joint and bursa injections
- **This can be used as opioid sparing therapy for patients**



# Let's take a walk through the literature...

## ORIENTEERING

---

### Palliative Care in Rheumatic Diseases: a First Approach

STEFFEN SIMON, Institute of Palliative Care, Oldenburg, Germany, and King's College London, School of Medicine, Department of Palliative Care, Policy and Rehabilitation, London, England, UK, MICHAEL SCHWARZ-EYWILL, Palliative Care Centre Oldenburg, Department of Internal Medicine and Rheumatology, Evangelisches Krankenhaus, Oldenburg, Germany, CLAUDIA BAUSEWEIN, King's College London, School of Medicine, Department of Palliative Care, Policy and Rehabilitation, London, England, UK

---

**Bottom Line:**  
Rheumatology patients need more access to palliative care

## RHEUMATOLOGY

### Editorial

### End-of-life care in rheumatology

*Room for improvement*

Rheumatology 2011;50:1187-1188  
doi:10.1093/rheumatology/keq364  
Advance Access publication 18 November 2010

**Bottom Line:**  
Rheumatologists need to identify patients in need and provide palliative care

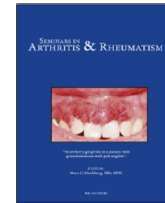
# Let's take a walk through the literature...



Contents lists available at [ScienceDirect](#)

## Seminars in Arthritis and Rheumatism

journal homepage: [www.elsevier.com/locate/semarthrit](http://www.elsevier.com/locate/semarthrit)



### Palliative and end-of-life care in rheumatology: High symptom prevalence and unmet needs

Jiacai Cho<sup>a,b</sup>, Jamie Zhou<sup>c,d</sup>, Dominic Lo<sup>e</sup>, Anselm Mak<sup>a,b,\*</sup>, Sen Hee Tay<sup>a,b</sup>

<sup>a</sup> Division of Rheumatology, Department of Medicine, Yong Loo Lin School of Medicine, National University of Singapore, NUHS, Level 10, NUHS Tower Block, 1E Kent Ridge Road, 119228 Singapore

<sup>b</sup> Department of Medicine, Yong Loo Lin School of Medicine, National University of Singapore, Singapore

<sup>c</sup> Department of Supportive and Palliative Care, National Cancer Centre Singapore

<sup>d</sup> Division of Palliative Care, Department of Haematology-Oncology, National University Cancer Institute, National University Health System, Singapore

<sup>e</sup> Department of Medicine, National University Hospital, National University Health System, Singapore



**Bottom Line:**  
**Patients and families in rheumatology are unnecessarily suffering**

# Let's take a walk through the literature...

**ABSTRACT NUMBER: 0061**

## **Rheumatologists' Attitudes Toward Palliative Care and Medical Assistance in Dying**

**Alexandra Saltman**<sup>1</sup>, Caroline McGuinty<sup>2</sup>, Gursimran Chandhoke<sup>3</sup>, Simon Oczkowski<sup>4</sup>, Heather McDonald-Blumer<sup>1</sup>, Ebru Kaya<sup>5</sup> and Kirsten Wentlandt<sup>6</sup>, <sup>1</sup>University Health Network and Sinai Health System, University of Toronto Faculty of Medicine, Toronto, ON, Canada<sup>2</sup>Ottawa Heart Institute and University of Ottawa, Ottawa, ON, Canada<sup>3</sup>Lakeridge Health, Oshawa, ON, Canada<sup>4</sup>Juravinski Hospital and McMaster University, Hamilton, ON, Canada<sup>5</sup>University Health Network,, University of Toronto Faculty of Medicine, Toronto, ON, Canada<sup>6</sup>University Health Network, University of Toronto Faculty of Medicine, Toronto, ON, Canada

**Meeting: ACR Convergence 2020**

**Keywords: Education, pain, quality of care, quality of life, Surveys**

**Bottom Line:**

**Rheumatologists don't know enough about palliative care**

# Let's take a walk through the literature...



## Residência **RP** Pediátrica

Publicação Oficial da Sociedade Brasileira de Pediatria

Submitted on: 06/07/2019  
Approved on: 06/11/2019

POINT OF VIEW

### **Pediatric rheumatology and palliative care for children: a most relevant match**

Esther Angélica Luiz Ferreira<sup>1</sup>, Hendrick Gramasco<sup>2</sup>, Simone Brasil de Oliveira Iglesias<sup>3,4</sup>

**Bottom Line:**

**Kids suffer from the same symptoms, plus more**

# Let's take a walk through the literature...

---

CONCISE REPORTS

## Palliative Care Utilization for Hospitalized Patients With Inclusion Body Myositis

*A Nationwide Study*

*Kamini Kuchinad, MD, MPH,\* Mahrukh Nadeem, MD,\* Ambereen Kurwa Mehta, MD, MPH,†  
David Shih Wu, MD,‡ Ché Matthew Harris, MD,‡ and Jemima Albayda, MD\**

Bottom Line:

Palliative care is underutilized in patients with Inclusion Body Myositis

# Let's take a walk through the literature...

> [BMJ Support Palliat Care](#). 2024 Nov 28:spcare-2024-005048.

doi: 10.1136/spcare-2024-005048. Online ahead of print.

## Palliative care in advanced systemic rheumatic diseases: an integrated approach

[Adam Amlani](#)<sup>1</sup>, [Kirsten Wentlandt](#)<sup>2</sup> <sup>3</sup>, [Alexandra P Saltman](#)<sup>4</sup> <sup>5</sup> <sup>6</sup>

Affiliations + expand

PMID: 39609074 DOI: [10.1136/spcare-2024-005048](#)

**Bottom Line:**

Primer for primary care to understand rheumatic disease management in the context of palliative care

# Let's take a walk through the literature...

## Top Ten Tips Palliative Care Clinicians Should Know About Rheumatology

Shannon Herndon, MD,<sup>1</sup> Jack Kimball, PA-C,<sup>2</sup> Laura Ross, MBBS, PhD,<sup>3,4</sup> Sarah Homann, MD, MPH,<sup>5-7</sup> Maya N. Faison, MD,<sup>8</sup> Yu-Lin Amy Lee, MD,<sup>9</sup> Adam Marks, MD, MPH,<sup>10</sup> Sophia C. Weinmann, MD,<sup>1</sup> Mithu Maheswaranathan, MD,<sup>1</sup> David Leverenz, MD, Med,<sup>1</sup> and Christopher A. Jones, MD, MBA<sup>11</sup>



## Examining the Case for Palliative Care in Patients With Systemic Sclerosis

Julie C. McDonald<sup>1</sup> , Laura Ross<sup>2</sup> , Carolyn J. Wicks<sup>3</sup>, and Jennifer A.M. Philip<sup>4</sup> 

**ABSTRACT.** Systemic sclerosis (SSc) is a complex, multiorgan disease that causes substantial and progressive symptoms and impairs quality of life. International guidelines recommend early, integrated palliative care for patients with advanced cardiopulmonary disease, such as heart failure and interstitial lung disease, as this care can improve patient, caregiver, and healthcare outcomes. In this article, we examine the potential need and role for palliative care in SSc. We propose that early, integrated palliative care could improve symptom control and quality of life and recommend a research agenda for palliative care in SSc to address the lack of evidence in this area.

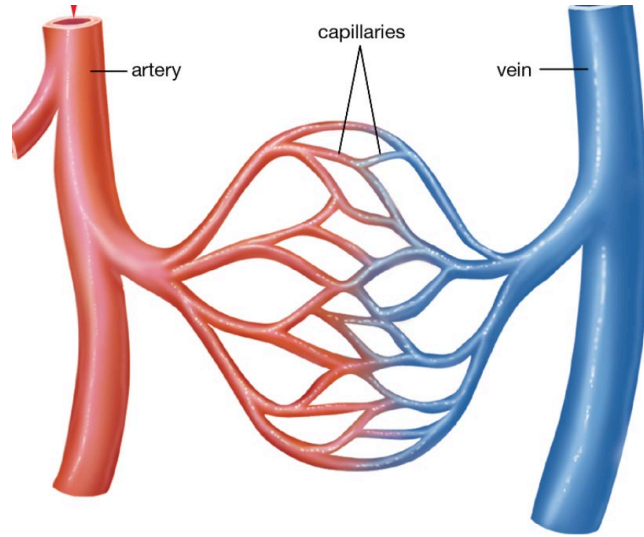
*Key Indexing Terms:* caregivers, palliative care, patient-centered care, quality of life, symptom burden, systemic sclerosis (systemic scleroderma)

## Quantifying the Need for Specialist Palliative Care Management in Patients With Systemic Sclerosis

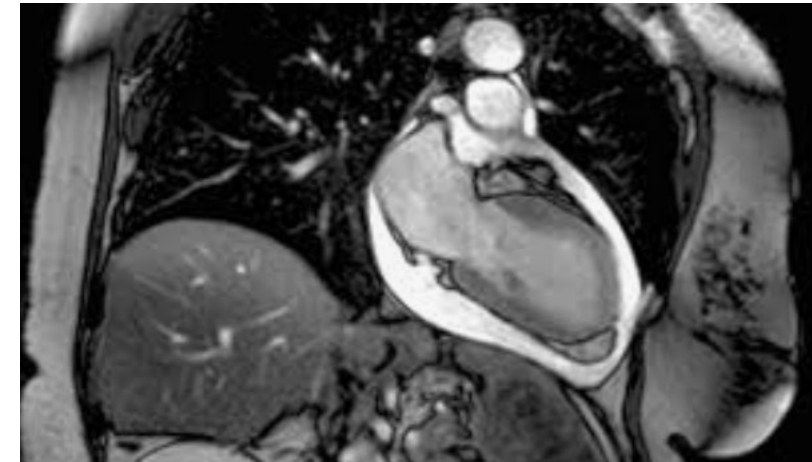
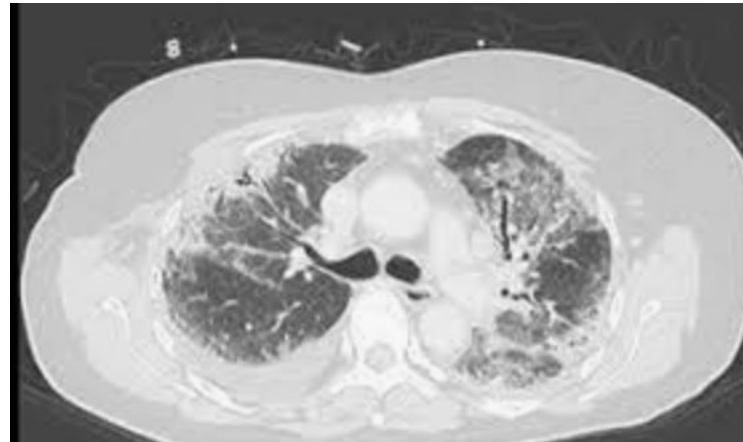
Laura Ross,<sup>1</sup> , Julie McDonald,<sup>1</sup> Dylan Hansen,<sup>2</sup> Jessica Fairley,<sup>1</sup> , Carolyn Wicks,<sup>2</sup> Susanna Proudman,<sup>3</sup> Jennifer Walker,<sup>4</sup> Joanne Sahhar,<sup>5</sup> Gene-Siew Ngian,<sup>5</sup> Lauren Host,<sup>6</sup> Wendy Stevens,<sup>2</sup> Jennifer Philip,<sup>7</sup> and Mandana Nikpour<sup>8</sup>

Bottom Line:

Physical and mental symptom and caregiver burden, early integration and collaborative care is needed, ACP is important



# INFLAMMATORY



Treatment: Immunosuppression or Immunomodulation

# IMMUNOSUPPRESSION/IMMUNOMODULATION

## GLUCOCORTICOIDS IN THE SHORT TERM

- IM Kenalog
- Intra-articular glucocorticoids
- Oral glucocorticoids

## DMARDS IF LONGER TERM NEEDED

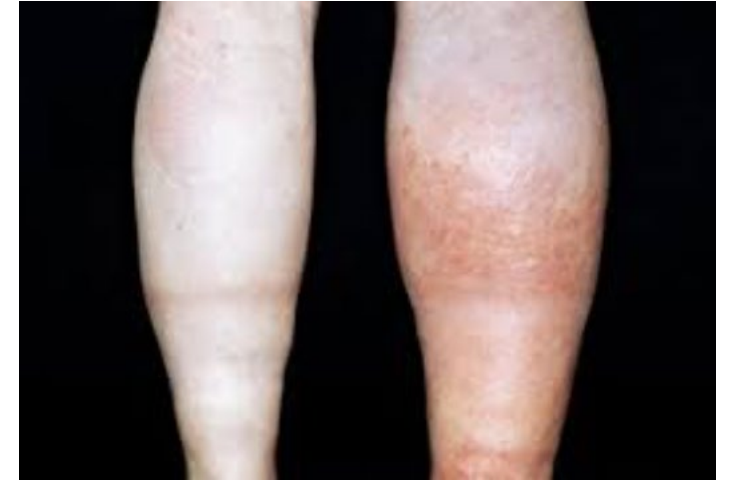
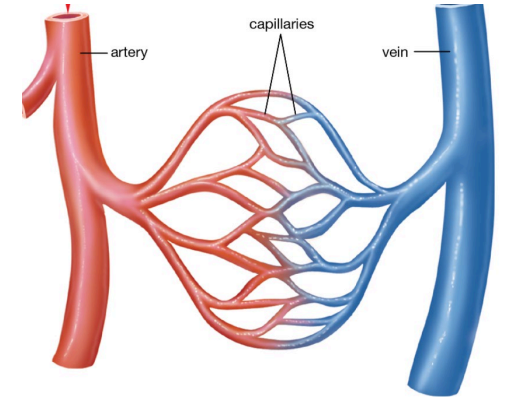
- Call Rheumatology

# FIBROTIC



Treatment: Standard palliative care treatment for symptoms

# VASCULAR



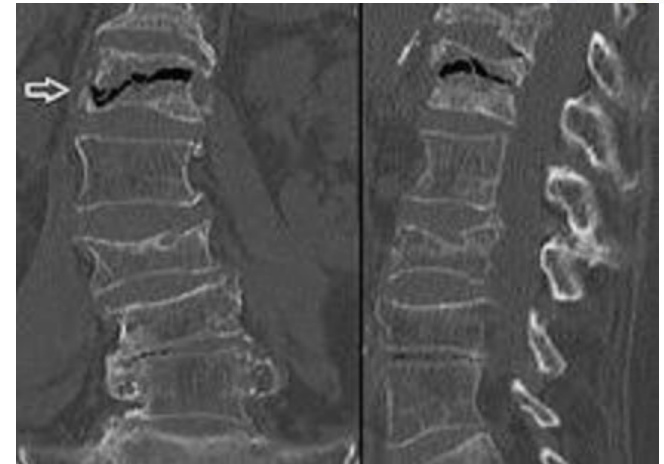
- Treatment: Trigger avoidance, Vasodilatation +/- Anticoagulation/Antiplatelet therapy

# TWO KEY SITUATIONS TO REMEMBER

- SCLERODERMA – DO NOT GIVE HIGH DOSE STEROIDS (Above 15-20mg daily)
  - Scleroderma renal crisis
- RAYNAUDS – DO NOT GIVE BETA BLOCKERS
  - Can potentiate further ischemia



# MECHANICAL



- TREATMENT: Conservative therapies, injections, standard pain control, surgical

# Rheumatology Medications in Palliative Care

# Key Principles



- What is the rheumatologic problem? What would be the consequences of a flare?
- What are the side effects of the medication? How is the patient tolerating the medication?
- What is the half life of the medication in relation to the prognosis of the patient?
- What is the burden of administration? What are the patient's feelings surrounding this?
- What are the interactions with palliative care medications?

# Key Principles



- What is the rheumatologic problem? What would be the consequences of a flare?
- What are the side effects of the medication? How is the patient tolerating the medication?
- What is the half life of the medication in relation to the prognosis of the patient?
- What is the burden of administration? What are the patient's feelings surrounding this?
- What are the interactions with palliative care medications?

# Key Principles



- What is the rheumatologic problem? What would be the consequences of a flare?
- What are the side effects of the medication? How is the patient tolerating the medication?
- **What is the half life of the medication in relation to the prognosis of the patient?**
- What is the burden of administration? What are the patient's feelings surrounding this?
- What are the interactions with palliative care medications?

# Key Principles



- What is the rheumatologic problem? What would be the consequences of a flare?
- What are the side effects of the medication? How is the patient tolerating the medication?
- What is the half life of the medication in relation to the prognosis of the patient?
- **What is the burden of administration? What are the patient's feelings surrounding this?**
- What are the interactions with palliative care medications?

# Key Principles



- What is the rheumatologic problem? What would be the consequences of a flare?
- What are the side effects of the medication? How is the patient tolerating the medication?
- What is the half life of the medication in relation to the prognosis of the patient?
- What is the burden of administration? What are the patient's feelings surrounding this?
- What are the interactions with palliative care medications?

# Common Medications

- Plaquenil
  - Half life 40 days
- Methotrexate
  - Half life 10 hours
- Leflunomide
  - Half life 20 days, but can stick around for 2 years
- Sulfasalazine
  - Half life 10 hours
- Prednisone
  - Half life 2-3 hours
- Biologics/JAK inhibitors
  - Variable half lives

# Interactions

Rheum Medication	Palliative Medication	Interaction
Methotrexate	NSAIDS	Increased concentrations of Methotrexate
Hydroxychloroquine	Antipsychotics, Methadone, SSRIs, antinauseants	Prolonged QT interval
Chloroquine	Antipsychotics, Methadone, SSRIs, Antinauseants, Mirtazapine, Trazodone	Prolonged QT interval, SSRIs can potentiate hypoglycemia
Leflunomide	Dexamethasone, duloxetine	Increased hematologic toxicity with dexamethasone, decreased effectiveness of duloxetine
Sulfasalazine	NSAIDS	Nephrotoxicity

# A note about steroids...

- IM Kenalog is your friend
  - Covers them for 6-8 weeks
  - Not a huge infection risk
- Intra-articular steroids
  - Most are not painful
  - Can last multiple months (on average 3 months)

# Ultimately...

- There are no hard and fast rules
- Usually a complicated risk-benefit decision, no harm in calling the rheumatologist
- Beware of drug interactions



# Thank you!

Happy to discuss any cases or questions!



# References

1. Bakitas MA, Tosteson TD, Li Z, et al. Early versus delayed initiation of concurrent palliative oncology care: patient outcomes in the ENABLE III randomized controlled trial. *J Clin Oncol* 2015; 33(13): 1438–1445.
2. Bourgarit A, Le Toumelin P, Pagnoux C, Cohen P, Mahr A, Le Guern V, et al. Deaths occurring the first year after treatment onset for polyarteritis nodosa, microscopic polyangiitis and Churg-Strauss syndrome. *Medicine* 2005 ; 84: 323–330.
3. Canadian Virtual Hospice. “What is Palliative Care.” 26 September 2017. [www.virtualhospice.ca](http://www.virtualhospice.ca). 6 May 2019.
4. Cho J, Lo D, Mak A, Zhou J, Tay SH. High Symptom Prevalence and Under-Utilisation of Palliative Care at End-of-Life of Patients with Systemic Rheumatic Diseases [abstract]. *Arthritis Rheumatol*. 2016; 68 (suppl 10). <https://acrabstracts.org/abstract/high-symptom-prevalence-and-underutilisation-of-palliative-care-at-end-of-life-of-patients-with-systemic-rheumatic-diseases/>. Accessed November 14, 2018.
5. Hawley P. Barriers to Access to Palliative Care. *Palliative Care Research and Treatment*. 2017; 1-6.
6. Higginson IJ, Bausewein C, Reilly CC, et al. An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial. *Lancet Respir Med* 2014; 2(12): 979–987.
7. Hospice and Palliative Care – Facts and Figures 2005. [[www.hospiceinformation.info/factsandfigures.asp](http://www.hospiceinformation.info/factsandfigures.asp)]
8. Kuriya B. Understanding the link between RA and CVD. Cardio-Rheum Day 2018. Women’s College Hospital. 14 September 2018.
9. Lynn J. Caring at the end of our lives. *NEJM* 1996; 335: 201–202.
10. Miller SC, Lima JC, Intrator O, et al. Palliative care consultations in nursing homes and reductions in acute care use and potentially burdensome end-of-life transitions. *J Am Geriatr Soc* 2016; 64(11): 2280–2287.
11. Morrison RS, Penrod JD, Cassel JB, et al. Cost savings associated with U.S. hospital palliative care consultation programs. *Arch Intern Med* 2008; 168(16): 1783–1790.
12. National Hospice and Palliative Care Organization. Facts and Figures: Hospice Care in America. 2017. [https://www.nhpco.org/sites/default/files/public/Statistics Research/2017 Facts Figures.pdf](https://www.nhpco.org/sites/default/files/public/Statistics%20Research/2017%20Facts%20Figures.pdf).
13. Park MC, Lee SW, Park YB, Chung NS, Lee SK. Clinical characteristics and outcomes of Takayasu’s arteritis: analysis of 108 patients using standardized criteria for diagnosis, activity assessment, and angiographic classification. *Scand J Rheumatol* 2005; 34: 284–292.
14. Pagnoux C, Guillevin L. How can patient care be improved beyond medical treatment? *Best Pract Res Clin Rheumatol* 2005; 19: 337–344.
15. Simon S., Schwartz-Eywill M & Bausewein C. Palliative Care In Rheumatic Diseases: A First Approach. *Journal of Palliative Care* 2008.
16. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 2010; 363: 733–742.