

ARE WE READY FOR EARLY PALLIATIVE CARE?

An Account of the Early Days of an Early and Integrated Palliative Care Initiative

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Janet M. Vandale, RN, MN, CNS



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PALLIATIVE CARE EARLY AND SYSTEMATIC

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- **Patents:** None





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PALLIATIVE CARE EARLY AND SYSTEMATIC

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for the early palliative
care guideline and
pathway!

"I will be forever grateful for the many acts of kindness, both big and small —that reassured both of us that we weren't alone, that others cared, and that her life was honoured and respected to its end."

(PaCES Patient/Family Advisor, on her mother's journey with cancer)

Vision:

Improving quality of life for Albertans with advanced cancer

Mission:

To provide early and ongoing access to coordinated, comprehensive and compassionate palliative care to improve quality of life for Albertans with advanced cancer

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Can we achieve *early & systematic* use of Palliative Care supports and positively impact patient-family and health care system outcomes?

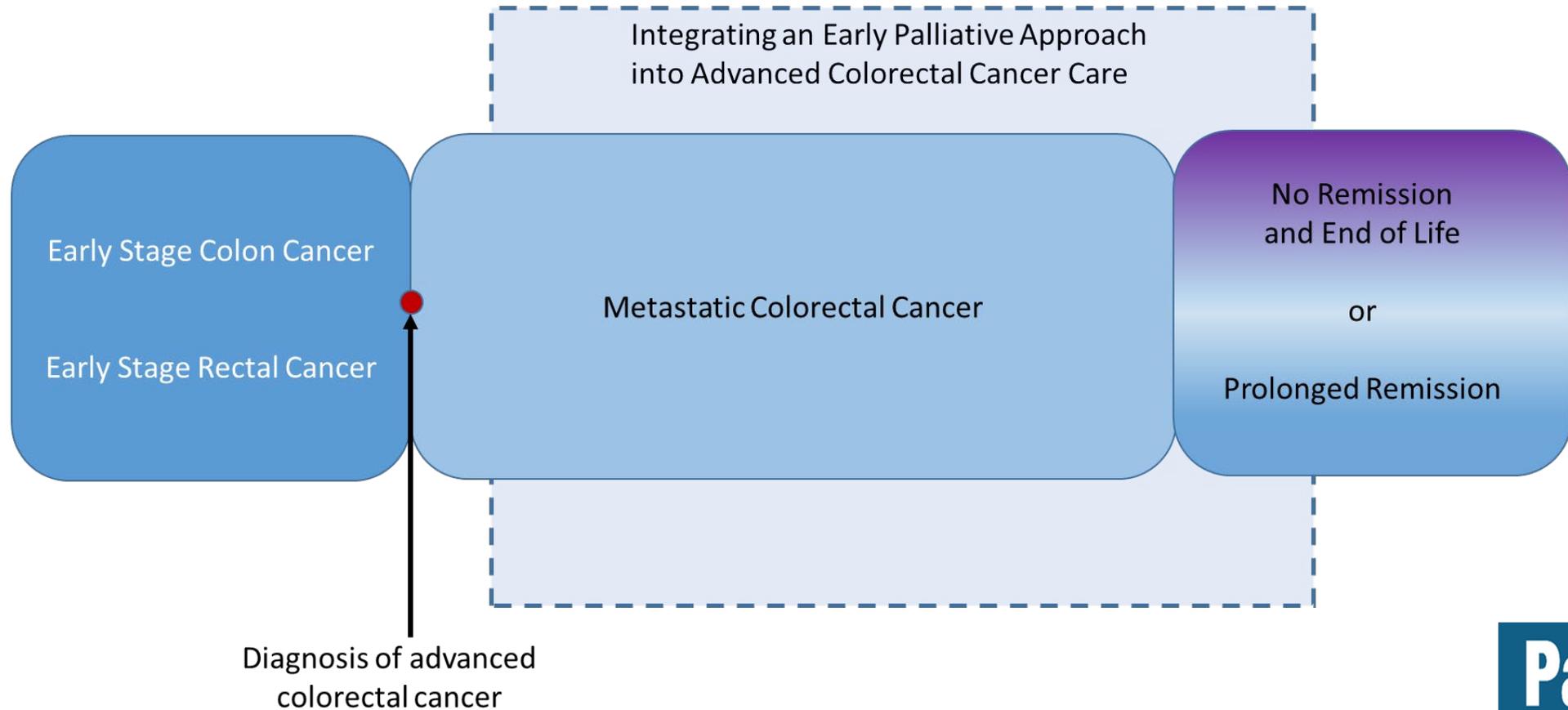
Yes, but....

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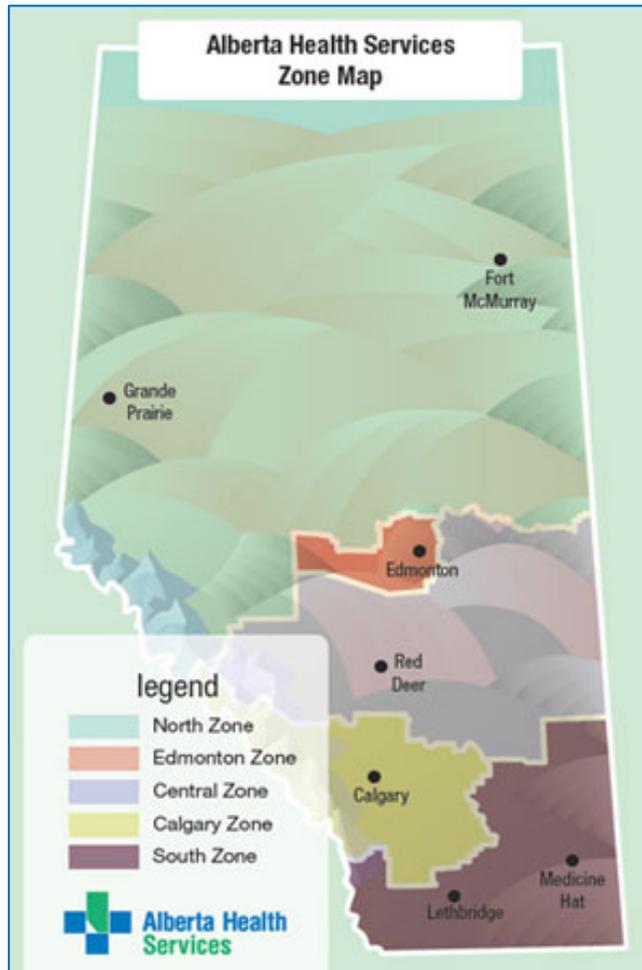
What do we mean by *early*?

A palliative approach to care that occurs concurrently with cancer treatment



The Problem:

Palliative Care has been accessed late in Alberta



Who: Colorectal cancer patients
What: Timing of palliative care (PC) access
Where: All AHS Zones
When: Deceased Jan 2011- Dec 2015
Why: Examine association health resource utilization

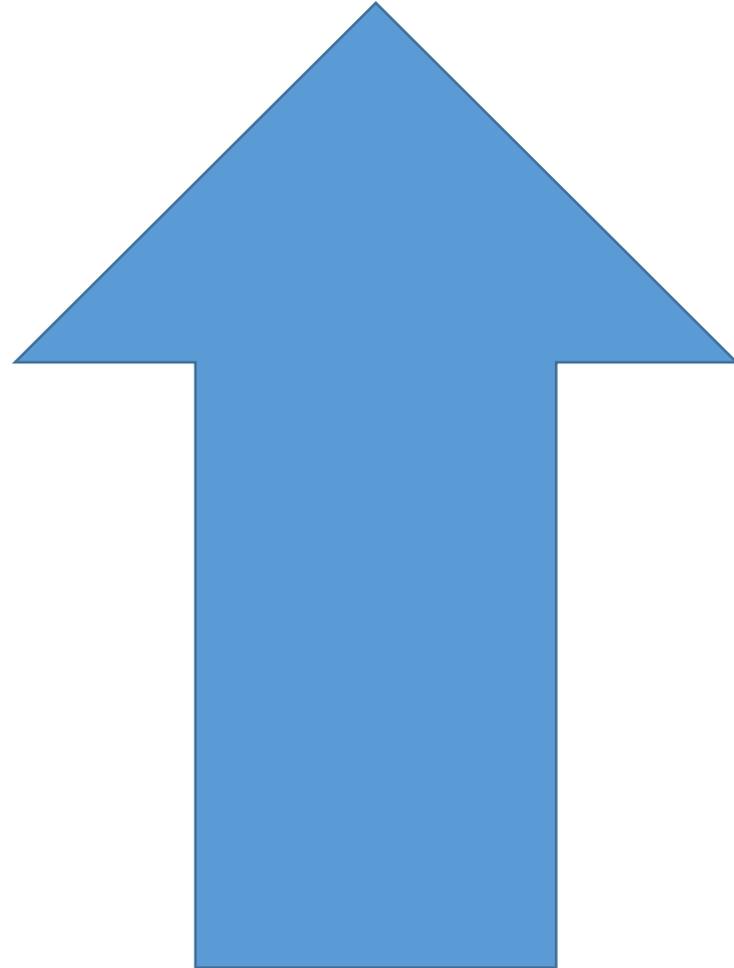
Region of residence at death (AHS Zone)	Median PC duration (days)	Range (days)
All Zones	51.0	0-3220
Calgary	56.0	0-2346
Edmonton	46.5	0-1782
North	40.5	0-1285
Central	29.5	0-1239
South	42.0	1-2155

On average, patient **first** accessed palliative care services **51 days** before death (varies by zone)

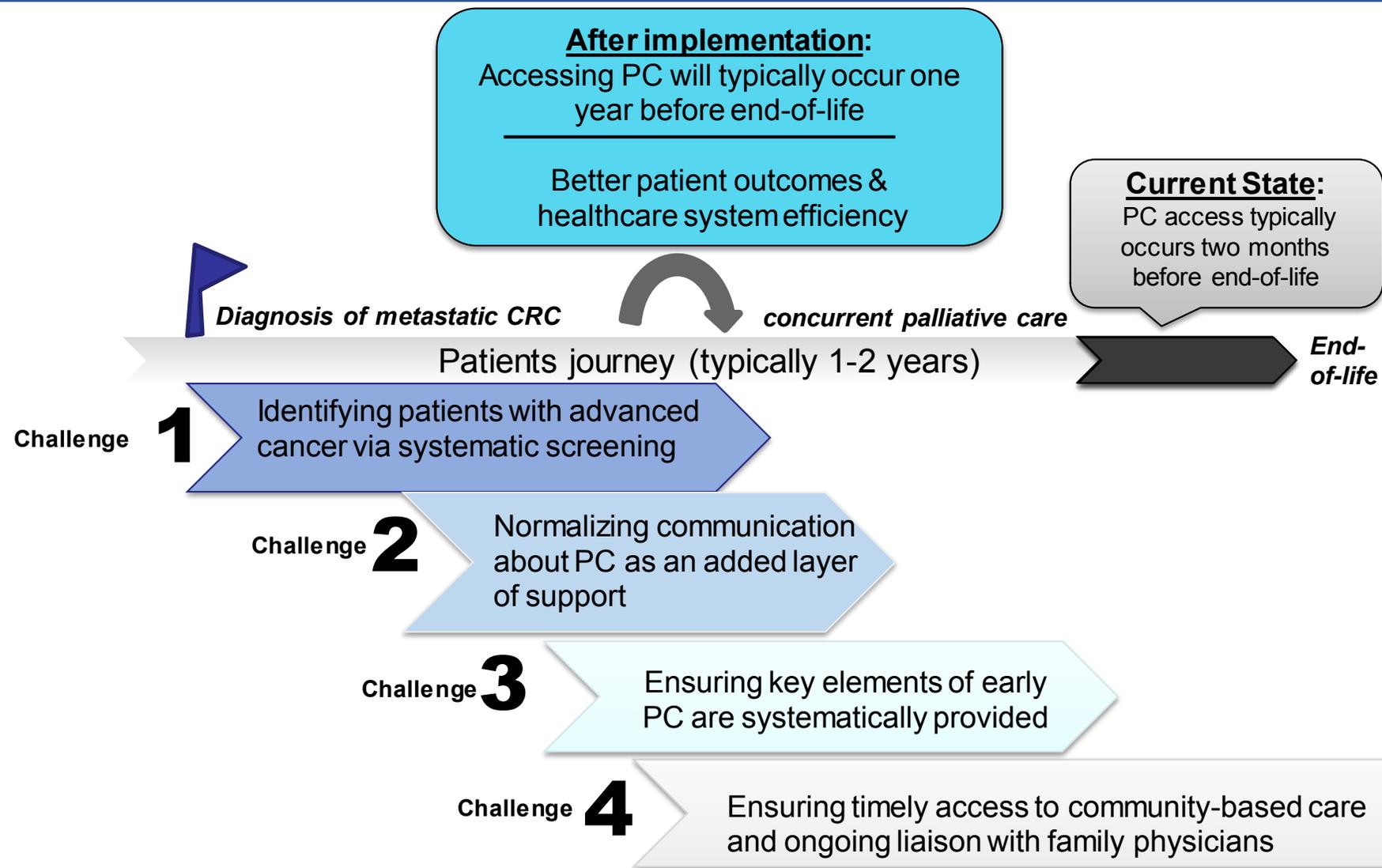


Our goal:

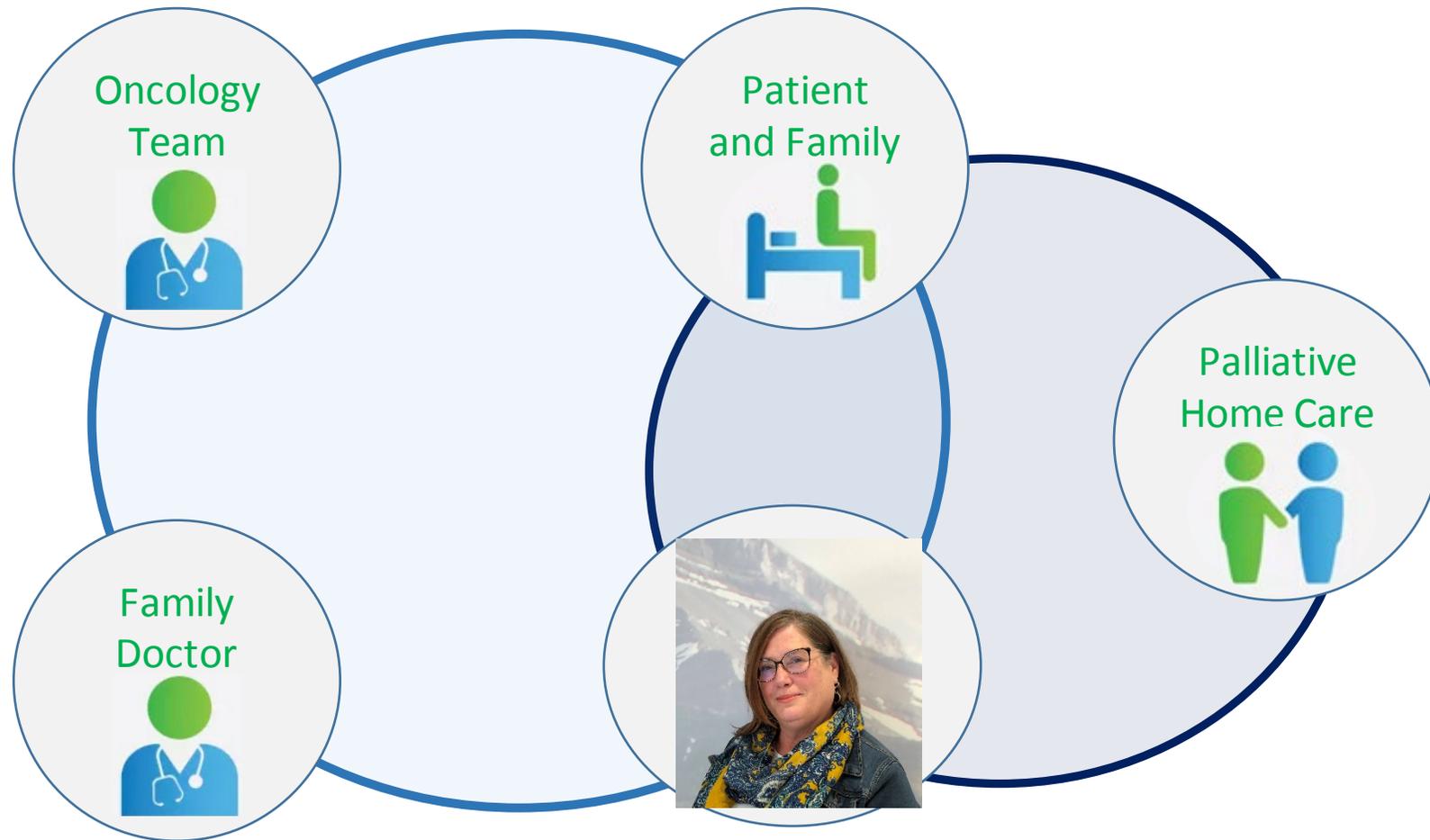
20%



Easy to say, harder to do in practice



Routine Early referral to PC nurse specialist



PC Nurse specialist – Jan. to Sept. 2019



47 Referrals

13 Deaths (5 home, 4 hospice, 4 hospital)

34 current (27 as case manager, 7 as consultant)



29 /47 “early”

Early Palliative care Elements





This is Susan...



Susan's 4 Elements:

Illness Understanding/Coping

- **HISTORY** of dramatic survival 2017 informs Susan's hopes and expectations;
- Worries about mother witnessing "inevitable suffering"

Symptoms/Function

- Pain is tolerable but has deeper meaning
- **History** of dying friend

HISTORY

ACP/Decision Making

- **HISTORY**
- Father's death, hidden illness
- Disturbing GCD discussion
- Friend's death in hospital informs Susan's desire to die at home
- Survival experience informs Susan's decision re: Lonsurt

Care Coordination

- Rural roots, "how things are done," health care and social community **HISTORY**
- Rural PCS as Susan's needs become greater



“Why would I plant a tree in my garden if I didn’t expect to see it grow?”

Emerging experience: from patients

I wish you (PC) had been introduced to us at the very beginning

I was afraid to ask what was coming, but it helps to have it out in the open. I feel like I don't have to push those thoughts away all the time.

I'll see you but you can't use the "P" word

We should just get sent to you when we're diagnosed instead of being asked if we want PC

But I don't need home care yet

No one has asked me about time and the quality of my life before

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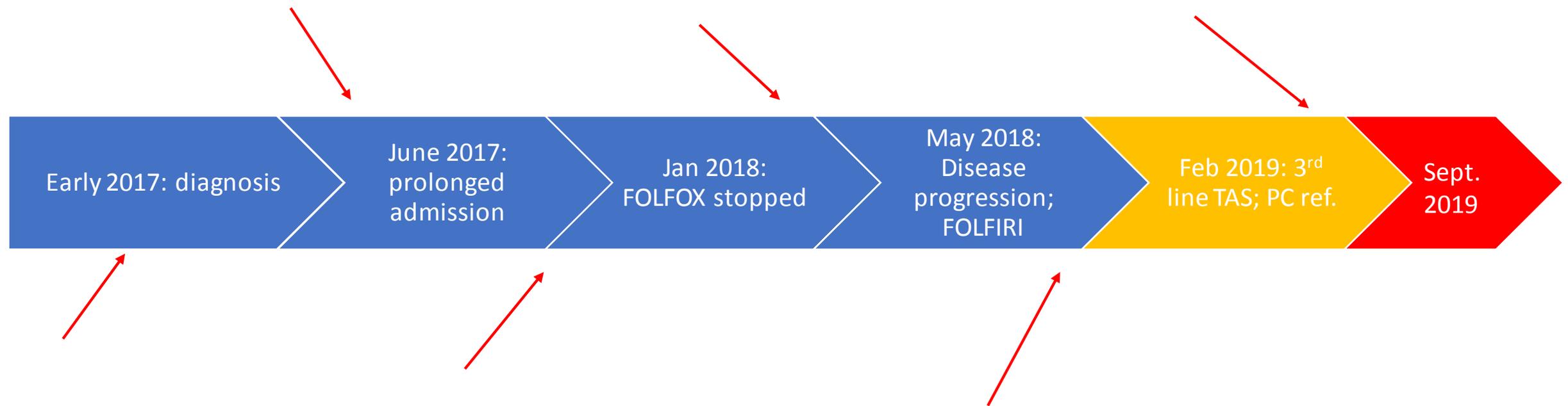
Emerging experience: from practitioners

No, he's not palliative yet.

But what are we doing for her? I'd like to get her off my list.

You would devastate her!

Susan's journey:



Essential learnings:

- PRESENCE
- LANGUAGE
- ONGOING CONVERSATION
- CULTURAL SHIFT





DAY 33

THEY SUSPECT NOTHING

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