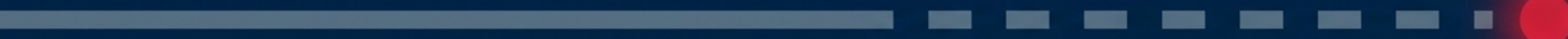


The Temporal Burden of Bleeding

A horizontal line spanning the width of the slide. The left portion is a solid light blue line, and the right portion is a dashed light blue line. At the far right end of the dashed line is a solid red circle with a soft red glow.

Anticipation, Care, and Time in
Von Willebrand Disease (VWD)

The Clinician's Horizon

Visit

Surgery

Delivery

**Clinicians see episodes.
Patients experience trajectories.**

The Patient's Horizon

Planning

Explaining

Worrying

Coordinating

VWD is lived before the event occurs. The bleeding may be episodic, but the anticipation is continuous.

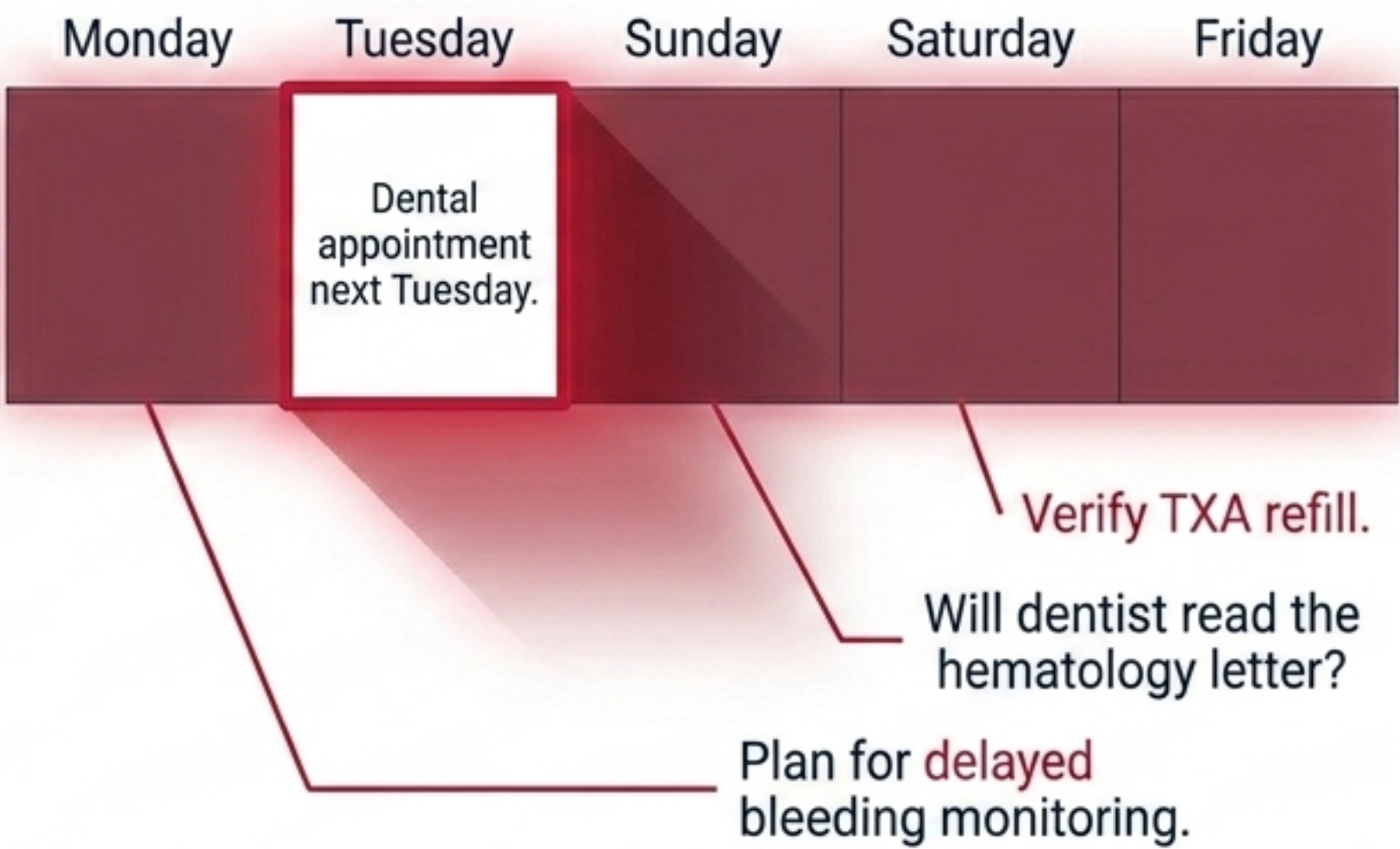
A Forecast-Based Illness

In many conditions, symptoms drive care. In VWD, the most important clinical event may not have happened yet. The diagnosis is a forecast. Same date. Different future.

Ordinary View

Monday	Tuesday	Sunday	Friday	Saturday
	Dental appointment next Tuesday.			

VWD View



Anticipation vs. Anxiety

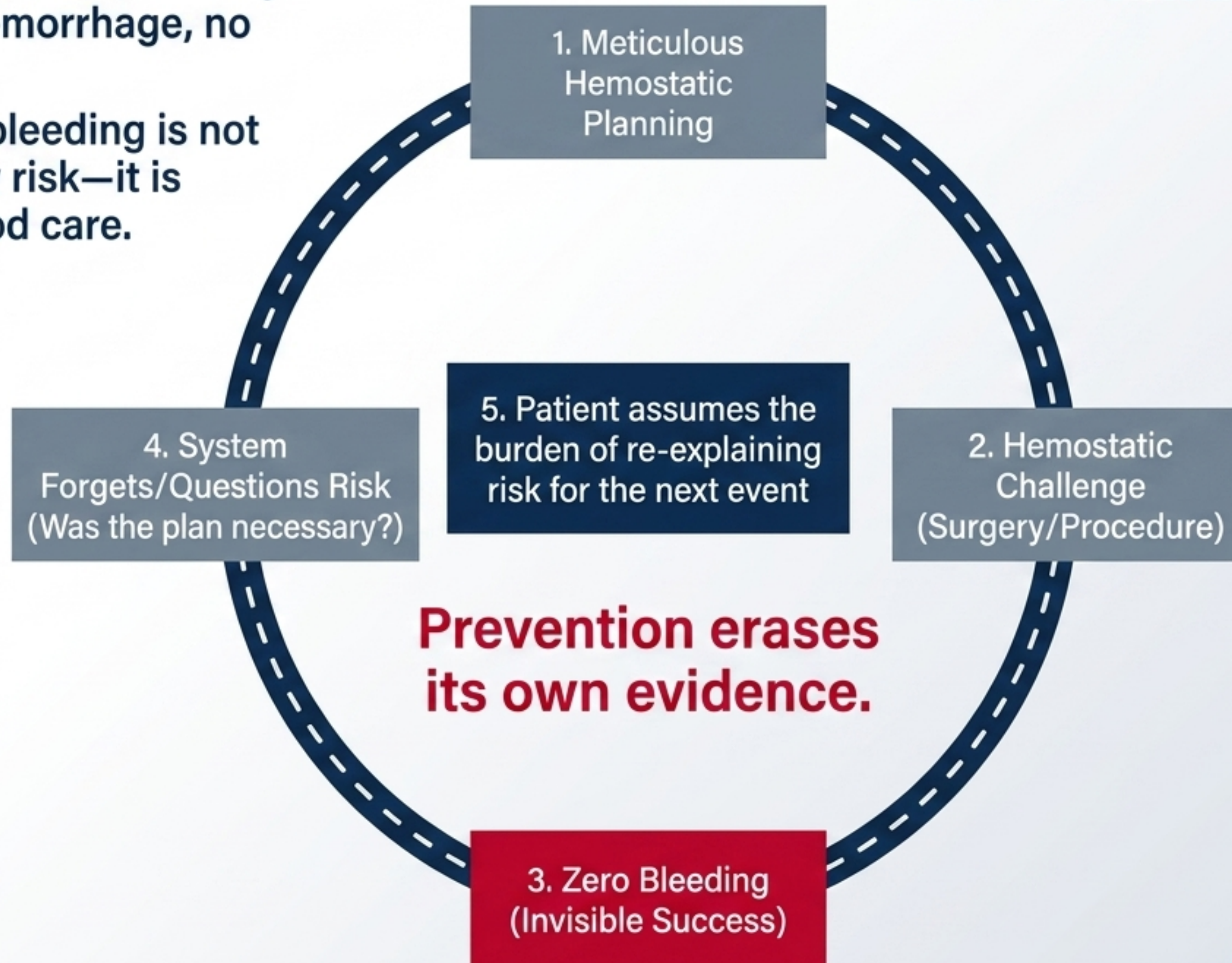
Generalized Anxiety	Bodily Memory
	
Imagines danger	Recognizes a pattern
Unbounded	Evidence-based
Hypothetical	Rooted in prior hemostatic failure (e.g., prolonged bleeding after wisdom teeth)

**Past bleeding makes future bleeding feel present long before it occurs.
In VWD, fear is often evidence-based.**

When planning works, nothing happens. No hemorrhage, no transfusion.

But prevented bleeding is not evidence of low risk—it is evidence of good care.

The Prevented Bleeding Cycle



The Hidden Infrastructure of Safety

Preparedness in VWD is a moral and practical labor. Patients must often plan for systems to fail, not just for bleeding to start.

The Moral Labor of Preparedness

Arriving for the
procedure

Acting calm, persuasive,
and grateful to be believed

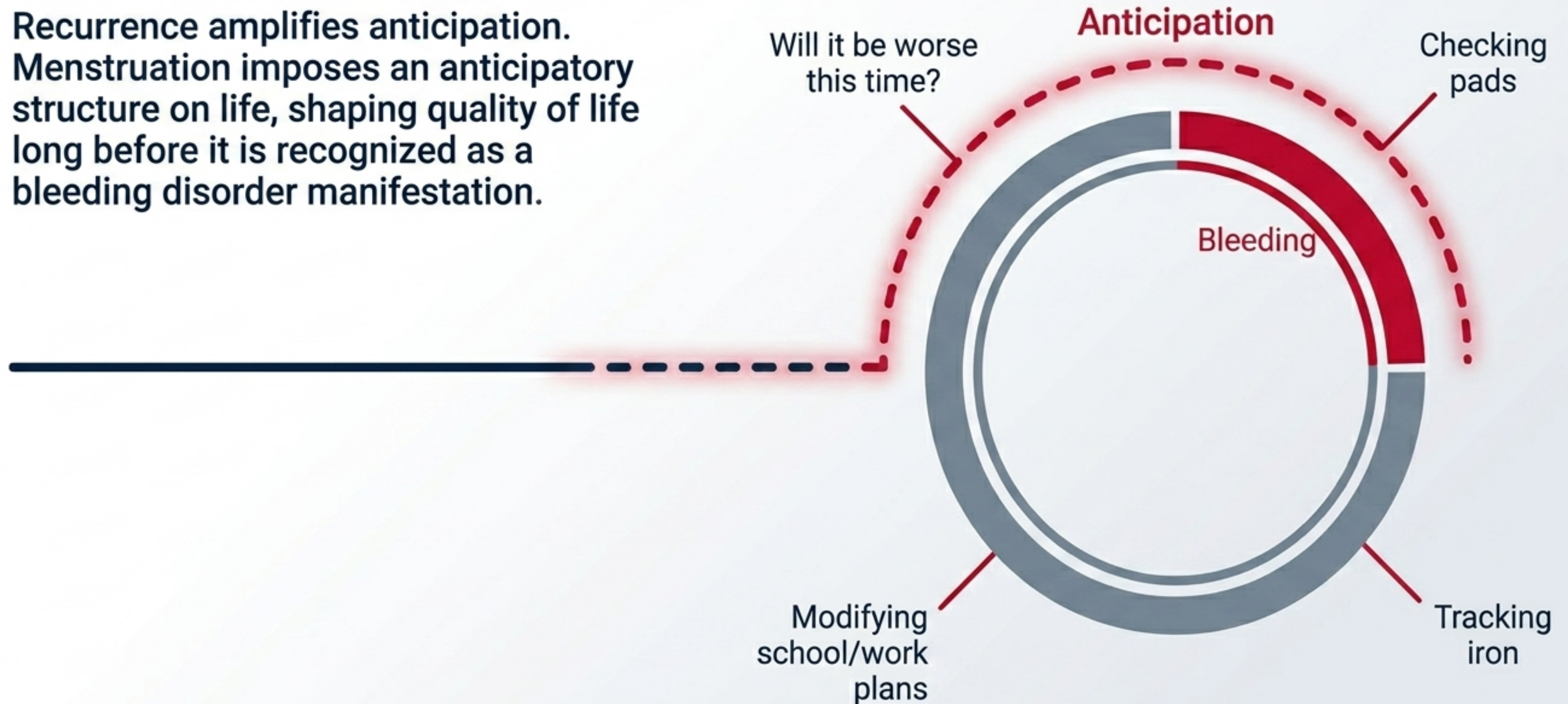
Verifying pharmacy has
VWF concentrate available

Requesting and carrying
hematology letters

Defending the diagnosis
to new providers

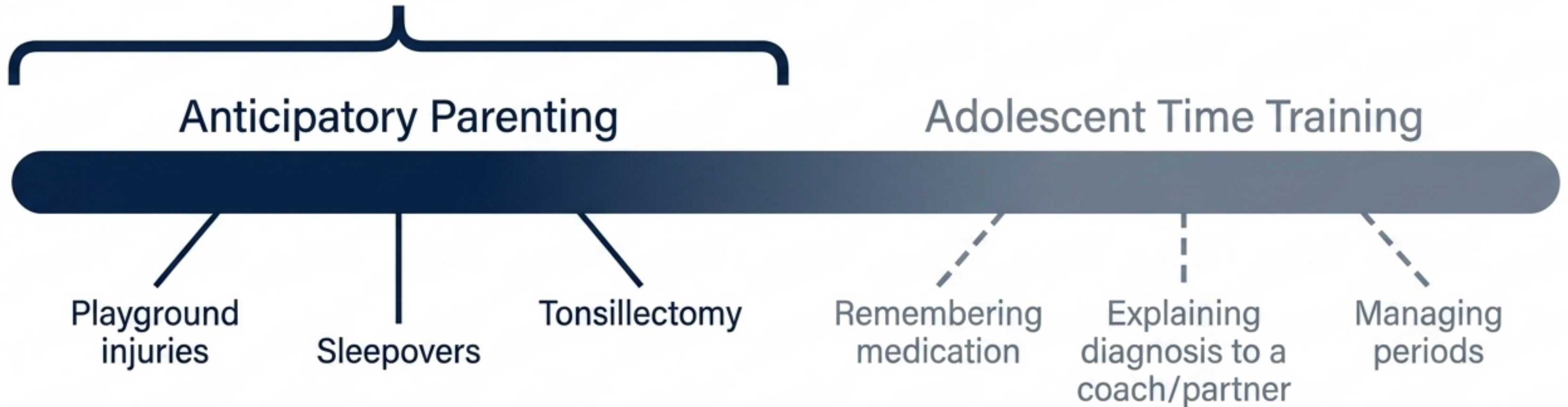
Heavy Menstrual Bleeding: The Monthly Negotiation

Recurrence amplifies anticipation.
Menstruation imposes an anticipatory
structure on life, shaping quality of life
long before it is recognized as a
bleeding disorder manifestation.



Transferring the Horizon: Childhood to Adolescence

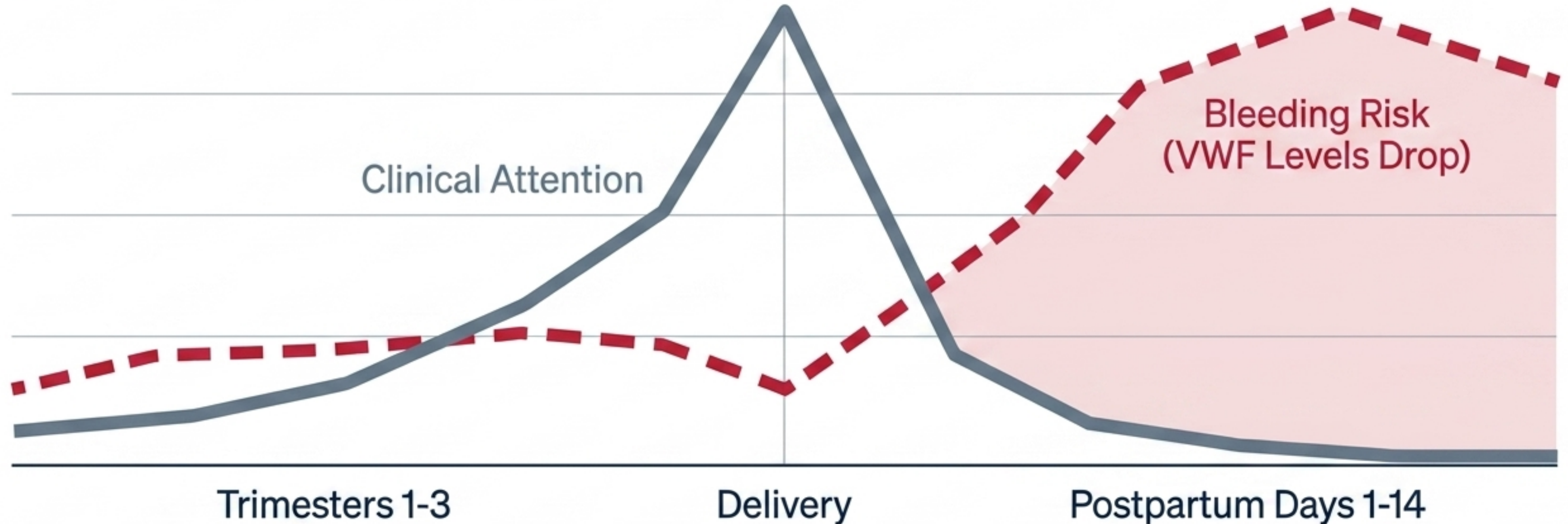
Parents carrying 100% of the forecasting burden



This transition is not just education; it is time training. The adolescent must learn how to carry the future without being dominated by it.

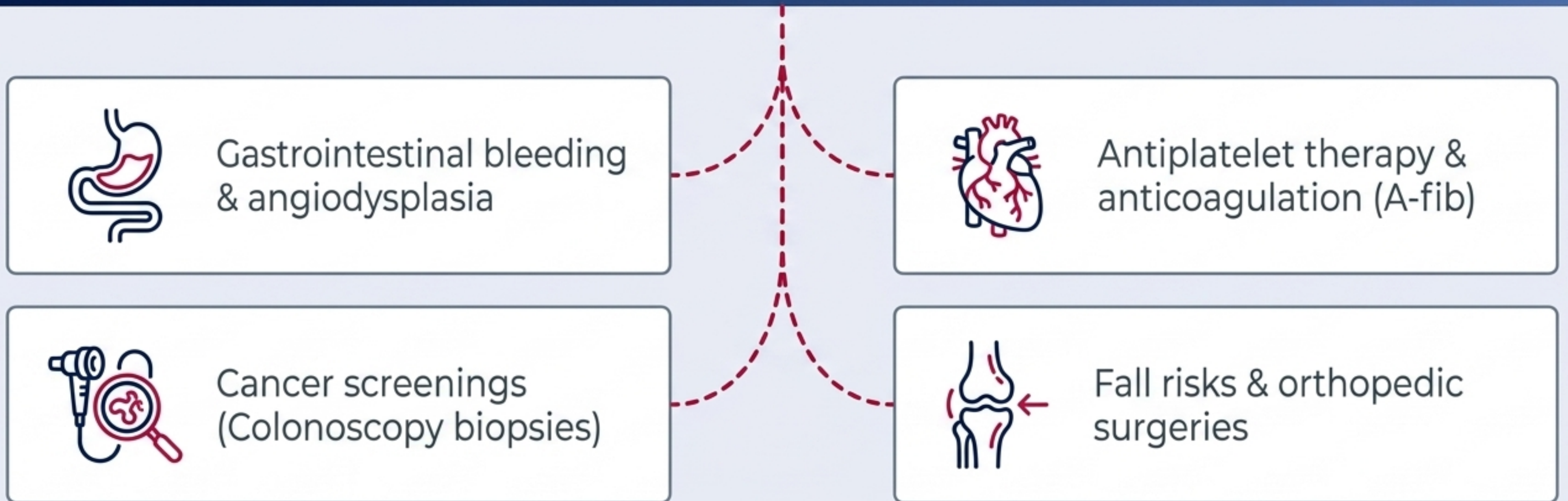
The Postpartum Blindspot

The highest-risk period follows the most monitored moment.
A delivery plan is dangerously incomplete unless it includes delayed postpartum bleeding instructions.



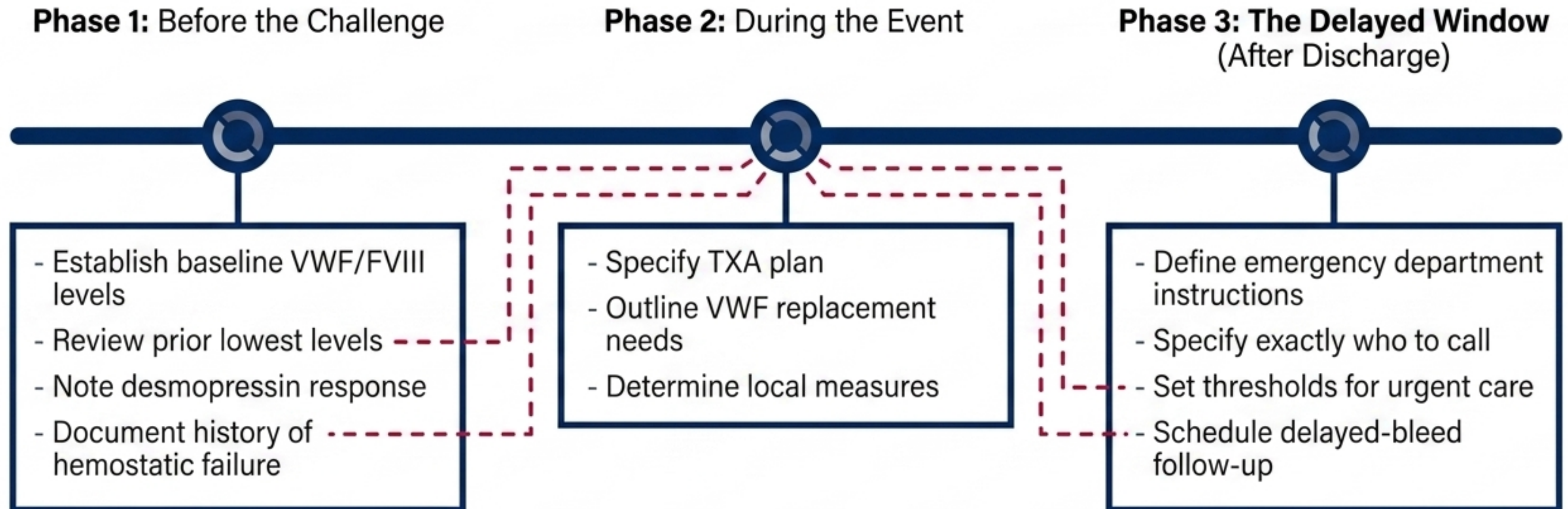
Aging: The Content Changes, The Structure Remains

Synthesized Insight: VWD is a life-course disorder because the future keeps changing. These risks require individualized balancing, not automatic avoidance of antithrombotic therapies or procedures.



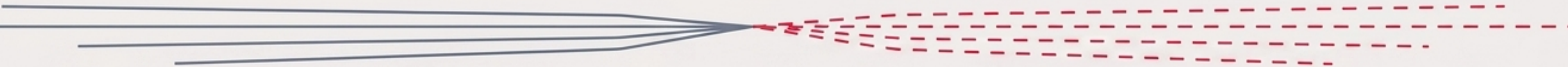
The Architecture of an Anticipatory Plan

Structure reduces existential uncertainty. A plan gives the patient a way to inhabit the future without being overwhelmed by it.



Changing the Clinical Lexicon

Synthesized insight: Anticipatory care should reduce fear, not enlarge it. Language that distinguishes memory from anxiety validates the patient's lived experience.



Instead of saying:	Try saying:
Try not to worry.	Your concern makes sense because you bled before. Let's use that history to plan.
The delivery should be fine.	The delivery plan looks reassuring, but we also need a postpartum plan because your prior bleeding happened after discharge.
Nothing happened last time.	Nothing happened means our plan worked.

Reflect & Apply: The Bleed That Matters Most



32-year-old pregnant woman, type 1 VWD. Uncomplicated first delivery, but suffered delayed postpartum hemorrhage on days on day 8.

Current third-trimester VWF levels are reassuring. She says:

"I'm not afraid of delivery. I'm afraid of the week after."

1. Acknowledge Memory

Validate that her fear of Day 8 is evidence-based predictive knowledge, not anxiety.

2. Look Past Reassuring Labs

Recognize that 3rd-trimester levels do not protect against the postpartum VWF drop.

3. Extend the Horizon

Write a plan that dictates TXA use and urgent-care thresholds for the two weeks post-discharge.

The Ultimate Goal: Calibrated Anticipation



The goal is not to eliminate uncertainty, but to calibrate anticipation. Good care allows the future to arrive without surprise, ensuring patients can live freely, not in fear.