



SURVIVORSHIP CARE PLANNING: A FEW THOUGHTS FROM FLYOVER COUNTRY

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THEN AND NOW



SCP: MISSION CRITICAL

- Patients must be effectively engaged in our own care
- At the patient's preference level, but let's not assume that we really mean "whatever you say, doctor..."
- My oncologist needs to learn every bit as much about me as s/he knows about my diagnosis, Sir William Osler, MD
- And I need to learn about my diagnosis and about my oncologist
- Only when we know and trust each other can we have a true partnership – during and after cancer treatment – and that takes time
- SCPs are a way to document what we both understand, to get on the same page, and to make sure my PCP is returned to the "A" team

#1 DIVERSITY & SILOES... GOOD NEWS/BAD NEWS

- Our health care system is a complex – often nonsensical – non-system, which is problematic for sharing what is known among clinicians and patients, and for framing guidelines
- EMRs are one giant meta-clinical trial – if only they weren't proprietary
- SCPs vary widely among organizations – good for creativity, bad for shared learning
- It seems there may be more efficient ways to build effective SCPs: we **MUST** capture patients' experience research, and we must share our research, and what we learn from our mistakes
- Can we create a virtual, asynchronous focus group so we can ask patients far and wide and deep?

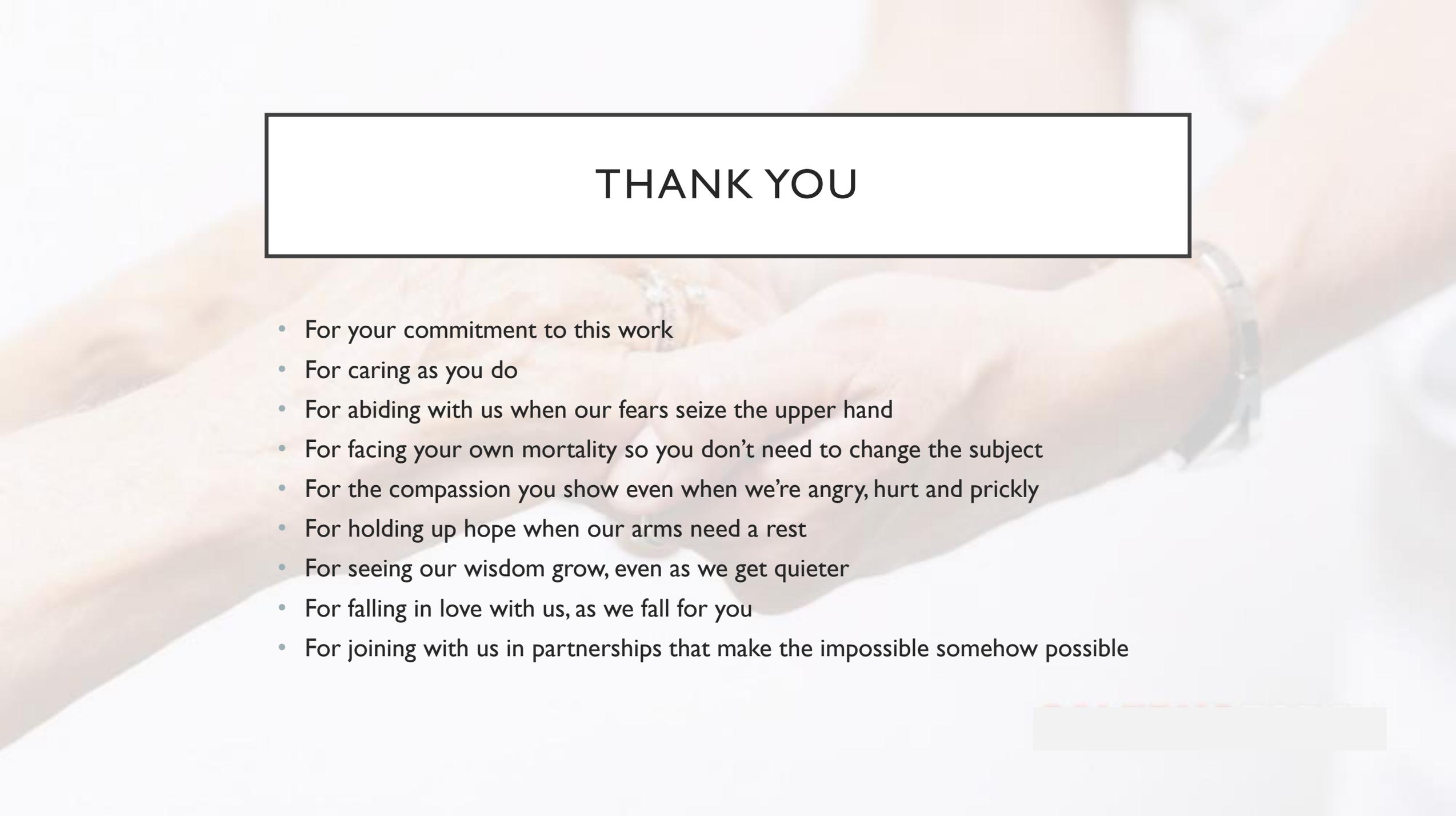
#2 THE TREES FOR THE FOREST

- SCPs are an important decisional tool, a conversation assist
- They facilitate; but they must NOT become the focus of care
- The focus of care remains the relationships. We mustn't become so enamored of the forest – the slickness of a plan – that we forget the trees. The value of the plan occurs in creating it, together
- “How come all of a sudden you don't care to scan or blood test me, when just last week it was all that mattered?": These conversations must happen. No matter how hard, you must explain to me why scans don't matter now, so I can come to terms with that, and make my own decisions about the way forward
- If I don't trust you -- which I won't if you withhold -- then this plan is useless



#3 BEHOLD THE WISDOM OF THE SHOE INDUSTRY

- They wouldn't DREAM of producing a line of shoes that haven't been vetted
- We MUST engage patients from the very start, at the very core of creating them
- From effective surveys ("what 3 things") → focus groups → patients as full team members on your SCP development teams
- DON'T LEAVE HOME WITHOUT US!
- Let's think about creating a virtual survivor consulting team
- We must tap into the rapidly evolving science of patient experience
- Wonderful tools to help! <https://www.hipxchange.org/PatientEngagement>



THANK YOU

- For your commitment to this work
 - For caring as you do
 - For abiding with us when our fears seize the upper hand
 - For facing your own mortality so you don't need to change the subject
 - For the compassion you show even when we're angry, hurt and prickly
 - For holding up hope when our arms need a rest
 - For seeing our wisdom grow, even as we get quieter
 - For falling in love with us, as we fall for you
 - For joining with us in partnerships that make the impossible somehow possible
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