

# “Being a Caregiver when you didn’t plan on it!”

PROSTAID Calgary Society

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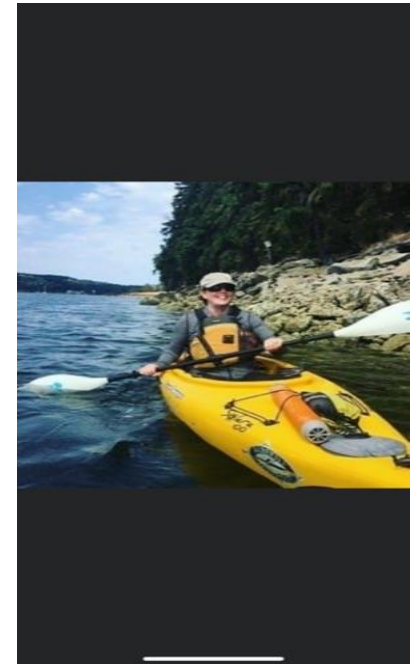
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# Today's Outline and Expectations – Caregiver 101

- Don's House Rules!
- Open and engaging – don't be afraid to ask!
  - Now is the time to ask someone who has lived experience like all of you and I will answer your questions.
- No Filter – “Unfiltered Therapy.”
  - Ask anyone!
- **“My Passion is Oncology Research and giving back.”**



# Unfiltered Therapy V1?

- What does being Unfiltered mean?
  - Open Discussion without fear of personal or peer perspective – I am here to answer your questions and to help share from my experience(s) without filter
  - 2 way conversation Peer to Peer
  - Advice to Clinical Teams and Researchers : Engage the Patient, Families, and Caregivers! DAY 1.....
  - Window Gaze: Recognize that the system needs work and it is an ongoing process (elephant in the room)
  - **If we always did what we always did – we are only ever mediocre!**



# Volunteer Background – Caregiver Perspective

- Co-Chair, Alberta Cancer Diagnosis (ACDI) Engagement and Design Initiative, Cancer Strategic Care Network, Alberta Health Services
- Steering Committee Member, Alberta Cancer Diagnosis (ACDI) Engagement and Design Initiative, Cancer Strategic Care Network, Alberta Health Services
- Core Committee Member, Cancer Strategic Care Network
- PFAC (Patient Family Advisory Committee), Tom Baker Cancer Centre and “New” Calgary Cancer Centre
- University of Alberta Kaye Competition Review Committee – Family Advisor
- Albertans4HealthResearch.CA (AB4HR) Advisory Council – Guest Speaker
- Advanced Tumor Diagnostics Day (UofC, AHS) - Guest Speaker, Panelist
- AbSPORU PCT (Pragmatic Clinical Trials) Certificate – Guest Speaker X4
- 3CTN (Clinical Trials Network) – Family Advisor for TBCC and Foothills Hospital
- ACF (Alberta Cancer Foundation) – Guest Speaker, Panelist for 2 Research Award Grants
- PFAN (Patient Family Advisory Network), Alberta Health Services ~ 20 Working groups in the last 3 years
- CCRA (Cancer Health Services Research: Patient Priorities) – Family Advisor
- Canadian Cancer Society – Patient Engagement in Research Panelist and Technical Research Reviewer
- University of Calgary Cuthbert Lab (Oncology Outcomes) Patient and Family Advisory Committee
- Technical Board of Advisors , Qualisure Diagnostics Inc.
- Corporate Community Relations – AGAT Foundation and AGAT Labs



# Volunteer Recognition and Driving Awareness for Cancer



BE HUMBLE



# What is a Caregiver?

“Caregiver” is a general term referring to anyone who provides care for a person who needs extra help. This could mean a family caregiver, a respite caregiver, a home caregiver, or a primary caregiver, to name but a few.





# One of the hardest roles ever! What it means to me.

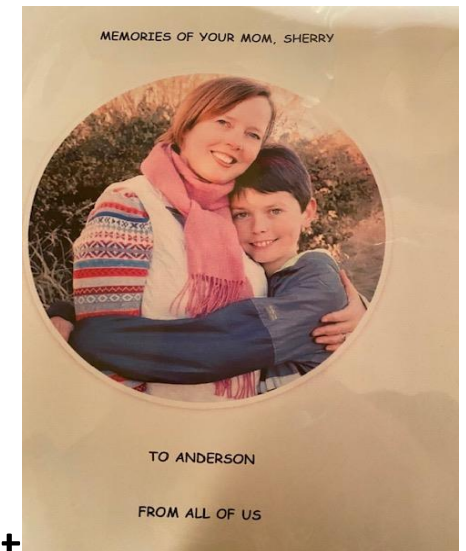
A caregiver can be anyone – Patient, Family Member, Friend, Colleague, Hired Professional – there is no identification or stigma attached.





# Sherry and Don's Team Journey - Medical History and Reflection 2017- 2020

- Medical History –
  - Cancer Diagnosis 2017
  - 3 Surgeries, 29 Rounds of Chemo, 6 Rounds of Antibody treatment
    - Outcome – Tumors continued to grow, treatments stopped early February 2020
  - Naturopath, Reiki, Massage, Homeopathic Remedies, etc.
  - Transition and reflection time – a new challenge
    - Potential Oral Chemo – Not covered by AHS
    - Potential Clinical Trial search
    - Potential Alternative Experimental Therapies – Not covered by AHS
  - **Ultimately what was the QOL going to look like was the decision to ponder?**

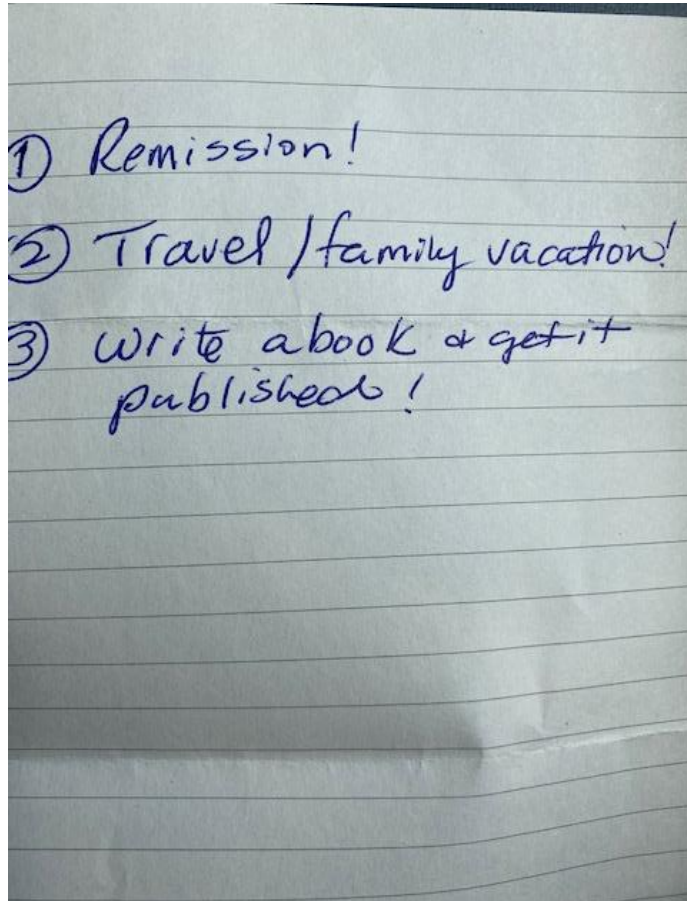


# Cancer isn't Contagious – Resources

- Call Wellspring - Week 1
  - Special people doing special work – we are all equal when we walk through the doors.
- Join PROSTAIID Calgary Society - Week 1
  - Engage with others on your journey who have lived experience like you.
  - Call a friend - a real friend, it's not contagious.
- Clinically
  - Make your Oncology Team “Your Team!”
  - Find a Nurse Designate for you if you do nothing else!
  - Engage right away with the Supportive Care (Palliative Team) - they are Angels without wings and will help you navigate, pain, medication, treatment, mental and emotional health, financial, any other topics you thought you would never have to think about.



# Why I am here today as a Caregiver Advocate?



**“Tough Slide so we will just talk it through – Passed away April 29, 2020”**



# Family Time Now

Holiday and time with Kids, Grandkids,  
Friends!

**“Keep your focus! Get out there”**

Granting Final Wishes!



# Staying Connected

Sherry used to send a happy picture to our Primary Oncology Nurse every month when she was feeling well.

I didn't know until after the Nurse let me know.

We have continued the tradition and will continue to do so – we remain friends – “mutual therapy”.



# *“STEAL WITH PRIDE” –*

## Tips From A Caregiver



Make all your relationships Peer to Peer – “TEAM WOOD”

Call everyone by their first name and make best friends with the Porter! They know the system and hospital better than anyone – awesome people with awesome stories!

LEARN LEARN LEARN as a Caregiver – from learning to read and interpret a lab report, to booking appointments, to booking a Virtual visit.

**CALL ME IF YOU ARE STUCK! IT IS ALL ABOUT YOU!**

**(403) 519-2225**

# Takeaways from today – Me to We to Us?

## Today

- Reflect and include the Patient and Family perspective always.
- Get out of your comfort zone!
- Stay positive!

## Moving Forward

- Implement what I have learned and take time to reflect...Always.
- Walk the Building!
  - Don says it is good therapy and is an even better reminder.



**“Make a commitment to yourself, your family; your Oncology team!**



# Thanks

Just Thanks!

“The Therapy helped today and thank you PROST AID Calgary Society and Dorothy for the opportunity to tell my story...It’s all about those who come after us”