

The essence of being the invisible half

Challenges of being a caregiver for Multiple Myeloma patients, a perspective
of a Myeloma doctor and caregiver

MM Fighters
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Objectives

- Introduction
- Definition of Caregiver
- Challenges
- Lessons learned and stories



Northwest Medical Specialties, PLLC



5 Locations throughout the South Puget Sound



21 Hematology Oncology / 8 Infectious Disease



Providers

4,500 new patients seen annually



1,700 of new oncology cases

annually

Bio


- Clinical Practice since 2001 after stem cell transplant training at Fred Hutch
- Specialized in breast cancer and Multiple Myeloma, Stem Cell Transplants
- Served thousands of patients and families
- Medical Director at NWMS, in charge of palliative care, survivorship, research, value based-care initiatives, and CEO of a national Oncology Network
- Founder of a non-for-profit to help families and patients through their journey

Story

“Let’s begin Dr. Blau’s story with a romantic encounter over a pencil. In 2000, Dr. Blau, who goes by Tony, met a woman named Sibel (who had trained in Istanbul and then in Cleveland) at Seattle’s Fred Hutchinson Cancer Research Center, specifically on the stem cell transplant ward. He was an attending physician; she a senior fellow. His pencil rolled under one patient’s closed door; a few seconds later it rolled back out: Sibel and Tony fell in love. She became an oncologist, he a cancer researcher, and they lived so happily ever after that eventually they joined forces to investigate one of the most recalcitrant types of breast cancer.”



The New York Times



Tony's Diagnosis

April 2015





Shock of a Cancer Diagnosis

- Devastating
- Overwhelming
- Scary
- Life changing

Cancer Caregiver

- The person who most often helps the person with cancer and is not paid to do so
- Partners, family members, or close friends
- Most often, not trained for the caregiver job
- Huge influence – both positive and negative – on how the cancer patient deals with their illness
- Helping patient stick with a demanding treatment plan
- Helping them to take other steps to get well, like eating healthy meals or getting enough rest

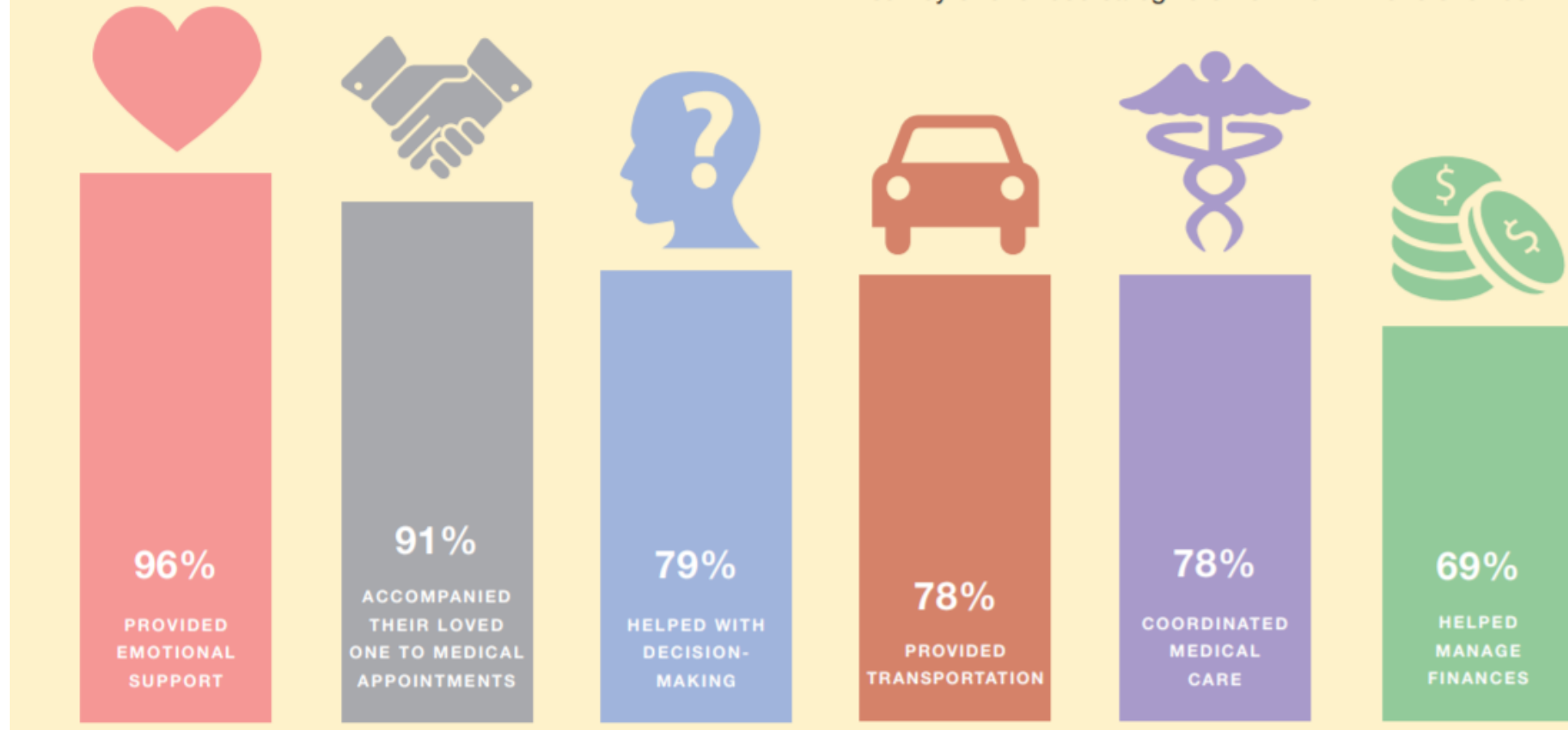
Roles of Caregivers

- Managing medications
- Taking care of a cancer patient
- Communicating with the health care team
- Financial and legal issues

Cancer patient caregiver

WHAT DO CAREGIVERS DO?

The CSC Cancer Experience Registry® allows us to learn more about the daily lives of caregivers. Many caregivers report that they are highly involved in medical care tasks. A survey of over 600 caregivers from 2014–2020 showed:



Doctor and Caregiver Sibel



Doctor

- Read all articles in every journal with his type of Myeloma
- Identified the doctor and all consultants
- Communicated with the oncologist frequently
- Involved with planning treatment

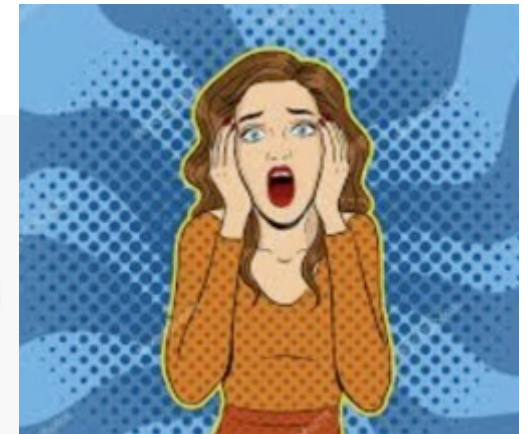
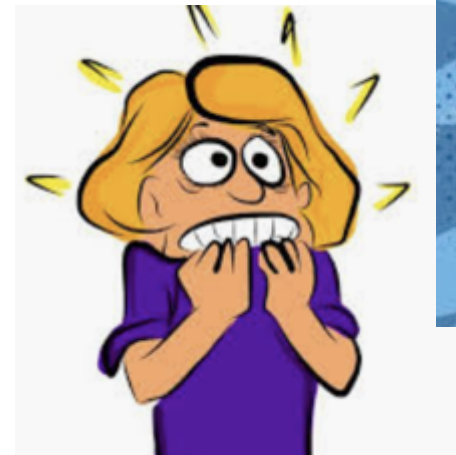
Caregiver

- Took time off during pivotal treatments
- Diet planning
- Clinic visits and transportation
- Managed medications and follow up plans
- Picked up prescriptions
- Managed insurance issues

Two worlds



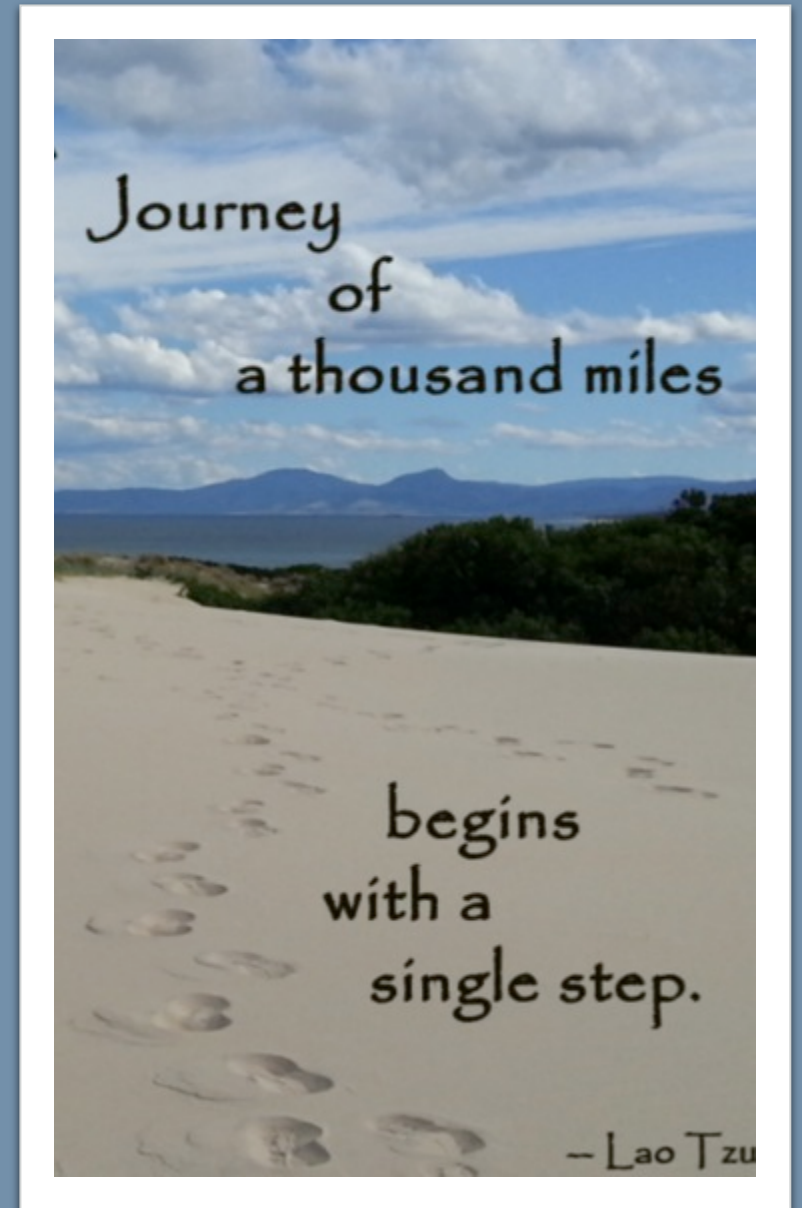
C101
CANCER101
Empower. Inform. Organize.



Lessons Learned

Lesson #1

- Learning to take one step at a time!



Taking Care of the Caregiver

- Set Limits
- Pace Yourself
- Control Stress
- Make Your Needs a Priority
- Know what you can't do – Ask others to help
- Early attention to signs of depression
- Take time to check on kids
- You can make mistakes





Lessons Learned

Lesson #2 You can make mistakes!



Treatment

- RVD
- Auto Stem Cell Transplant
- Allo Stem Cell transplant

Post-treatment complications

- Influenza requiring hospitalization after allo transplant
- Acute GVHD episode
- Zoster Encephalitis



Lessons
Learned
Lesson # 3



**FOLLOW
YOUR INSTINCTS**
STRAIGHT AHEAD

Maintenance

- Treatment
- Follow up



Lessons Learned Lesson #4





Feeling Guilty

Feeling Guilty

- Not for being the sick one
- Not for not giving enough care
- Not for making mistakes

- **But for thinking of the future and “what if” question comes to mind**



TOMORROW

TODAY

YESTERDAY

**FOCUS ON
TODAY.**

Goals as a Caregiver

- Take care of your loved one
 - Take care of yourself
 - Enjoy the moments you have
 - Create memories
 - Don't postpone plans, live it today
-
- And don't feel guilty for being a human being

Myeloma Cure

- New Therapies
- Advancing Research
- Data Sharing Platforms
- Support Groups



Conclusion

- Take one step at a time
- Learn your loved one's needs and personality dealing with cancer
- Follow your instincts
- Take care of yourself
- Focus on today
- Don't feel guilty for feeling like a human
- Get help, communicate and keep learning
- It is not a sprint, it is a marathon

Thank You!



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