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## Decision making and resilience

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# My research

## Study 1:

'Myeloma Community'

Interviews and observation

Myeloma support groups Wisconsin, USA

## Study 2:

Myeloma Support Group Leaders

Motivations/Barriers/Resilience

Interview and observation



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# Today's talk

- Ottawa Personal Decision Guide – a tool for decision making <https://decisionaid.ohri.ca/odsf.html>
- Making decisions and the decision process
- The power of stories
- Resilience in decisions and in leadership
- Workshop – look at tool, share perspectives and tips

# Decision making in myeloma

Decisions offer opportunity for collaboration control, empowerment - *options*

Decisions also offer uncertainty, risk, the unknown, doubt (**trust**)...fear...

Newly diagnosed: Upfront decision making at diagnosis  
– SCT? Which doctor or centre?

Maintenance decisions, pain relief, side-effects

Decisions when m-spike is rising or at relapse

“Crisis” and “critical” decision making

*“The issue of transplant is the most prevalent, difficult decision, I think that every myeloma patient faces”*



# Key elements of the Ottawa tool


- ✓ It asks *simple* questions:
- ✓ Clarifies the decision at hand, reasons and timeframes
- ✓ Allows us to think about priorities
- ✓ Allows the mapping of knowledge/knowledge gaps
- ✓ Can see the effects of others on your decisions e.g. support for/pressure on your decision
- ✓ Highlights the collaborative nature of decision making
- ✓ Allows us to think about what role we want in decision making....not everybody wants to take the lead (or is able to).

# Degner et al (1997) Solari et al (2013)


I prefer to make the final selection about which treatment I will receive



I prefer to make the final selection of my treatment after seriously considering my doctor's opinion



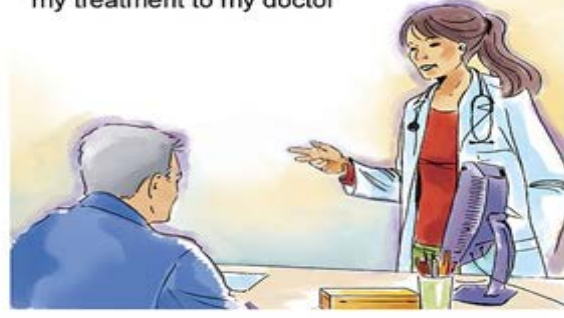
I prefer that my doctor and I share responsibility for deciding which treatment is best for me



I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion



I prefer to leave all decisions regarding my treatment to my doctor





# Key elements of the Ottawa tool

- ❖ Highlights barriers and gaps which impede decision making – what are your decision making needs
- ❖ Takes focus from options and outcome to think about *how we make decisions*
- ❖ Allows us to think of decisions as a *process*
- ❖ Is a springboard for *sharing decisions* and *discussing* them
- ❖ Allows the planning of next steps in treatment and decisions

*“Information can be a great salve, if it comes from a trusted source. Oftentimes, it need to come from more than one source, including the healthcare team and other experienced patients.”*

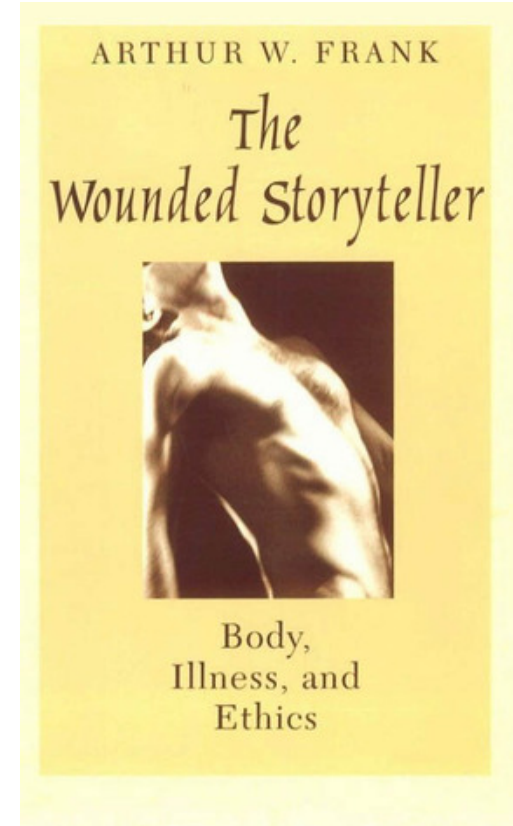


# Where support groups fit in: the power of stories

*“The ill person who turns illness into **story** transforms fate into **experience**; ...[a]s wounded, people may be cared for, but **as storytellers, they care for others.** The ill, and those who suffer, can also be **healers.**”*

(Arthur Frank 1995: xi-xii).

*Turning experience into knowledge*







# Where support groups fit in: the power of stories

**Daniel:** *“You just don’t get the pros and cons and things with your doctor, you don’t understand treatment options, what’s coming down the pipe... I was at one of the support group meetings and we were just going around the room talking about things and [the group leader] mentions “Daniel is thinking about a transplant”. So they kinda went around the room, and as you know in these groups um, **it’s just a great big pot of everything you can think of, every combination of something that people have gone through...** So that group is real important. I come back with stuff from the group that I bring to my doctor: “Why aren’t we looking at this or that? **When are we going to be testing for this? You know, what’s the future treatment plan?**”*



Try reminding members of the power of their experience at the start of meetings – support groups are about **giving and getting.**



# What is resilience?

**Resilience:** The capacity adapt in the face of adversity, trauma and stress  
(resilience is not about “bouncing back” )

Key to personal resilience (in general):

- ✓ Having a plan and options within that plan (and being able to carry these out)
- ✓ Confidence in your own abilities and knowledge
- ✓ Skills in problem diagnosis and solving
- ✓ Supportive relationships encourage resilience





# Resilience and “crisis” decisions in myeloma

Decisions at relapse ( and/or when options are limited)

*“Facing the edge of the cliff again”*

Difficult to process information and to consider sources at this time

You need to have plan in place already – regimens, Drs, centres

Incremental gathering of information and knowledge is better (keep attending the SG!)

Clinical trials – consider the issue of vested interests



Why not have a group meeting focussing on this type of decision making? Focus on the HOW and WHY not just WHAT decision was. *Help your members build decision skills.*

# Resilience and decision making

***You can't regret your decisions***

**Mike Katz**

- ✓ Being able to live with strong feelings is central to resilience
- ✓ Being decisive and “owning” decisions builds resilience (*have you ever tried to change someone's mind?*).

<http://mam.myeloma.org/#>





# Resilience in leadership

## *What keeps you going?*

- Sources of resilience for group leadership – family, friendship, hope, faith, knowledge, science, the IMF
- Resilience is not about “bouncing back” – MM changes things, loss in SGs changes things
- The new person walking in the door – you've felt that fear
- Ideas, creativity, strategy, planning, leading
- Myeloma is changing disease – “excited” - passion





# Pathways for resilience in leadership

- Resilience for yourself, your group, for hope
- **Know your value:** *“I see every single meeting how we change attitudes and lives and it feels very important.”*
- **Get help:** steering groups, volunteers, co-leader, successor/s
- **Delegate:** NOW!
- Coping with loss: **space for reflection and ritual**
- **Groups within groups:** emotional support, end of life issues, carers
- Burnout and fatigue – adopt a **“childcare approach”**, you love your “baby” but sometimes you need a break, have a member “babysit” your group

Do you feel supported by your group?



# Discussion points and Q&A

The Ottawa document is in your pack – we are keen to know what you think....

- ❖ Is decision making an issue in your group?
- ❖ Is the tool helpful? To patients, to leaders, to groups?
- ❖ At what stage and which contexts?
- ❖ How would *you* use it? What do you do now?
- ❖ Can we add to it? e.g. work/life commitments and goals, repeat decisions
- ❖ In general: what would help you and your group members make decisions?



# Ways to think about using the tool

- ✓ Personally, for decision making
- ✓ In information packs
- ✓ For newly diagnosed patients and carers
- ✓ A group session on making decisions – how do you do it, how does it feel, avoiding regret, living with uncertainty
- ✓ In a caregivers session
- ✓ Ask family members and carers to complete it as well
- ✓ Members come and go – they may come back to meeting when making a decision
- ✓ Buddy system (small group or 1-to-1) to support decision making (but beware of vested interests and strong opinions)
- ✓ As a tool to start a conversation about how hard it can be to make decisions!



# Conclusions

Making decisions is HARD, emotional and intellectual WORK

Support groups are vital to decision making – patients should attend as early as possible after diagnosis and keep coming!

Information comes in many forms – patient stories carry knowledge for decision making. “how it was for me” is embodied information

Support groups are vital to MM Resilience

Leaders: find your own pathways to resilience, care for yourself!

*“After you make a decision you need a break!” John*

I AM A  
#MYELOMAWARRIOR





Thank you !

