





WHEN OTHERS SPEAK FOR YOU: SUPPORTING SURROGATE DECISION MAKERS

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OBJECTIVES

-  Understand the responsibilities and emotional burden of surrogate decision makers, especially in the context of dementia
-  Recognize ethical, legal, and clinical complexities when capacity is lost
-  Apply best practices to support and communicate effectively with surrogates
-  Identify red flags and know when to involve additional support services

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CONTEXT – DEMENTIA AND DECISION-MAKING

- 🧠 COGNITIVE DECLINE
 - GRADUAL LOSS OF MEMORY, JUDGMENT, AND REASONING
 - LIMITS ABILITY TO MAKE OR COMMUNICATE DECISIONS
- ⚖️ LOSS OF DECISION-MAKING CAPACITY
 - INABILITY TO MANAGE HEALTHCARE, FINANCES, OR LEGAL MATTERS
 - REQUIRES INCREASING SUPPORT FOR DAILY AND MEDICAL DECISIONS
- 👤 DEPENDENCE ON SURROGATES
 - SURROGATES MAKE CHOICES ALIGNED WITH PATIENT'S KNOWN OR INFERRED WISHES
 - SHIFTS CONTROL FROM PATIENT TO CAREGIVER OR LEGAL DECISION-MAKER

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THE LIFE ARC: FROM DEPENDENCE TO INDEPENDENCE AND BACK



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CONTEXT – DEMENTIA AND DECISION- MAKING

- ⚠️ RISK OF MISALIGNMENT
 - LACK OF EARLY PLANNING CAN LEAD TO CONFLICTS
 - FAMILIES MAY STRUGGLE TO INTERPRET WHAT THE PATIENT WOULD WANT
- 👤 THREAT TO IDENTITY AND DIGNITY
 - AUTONOMY IS TIED TO PERSONHOOD
 - PRESERVING DIGNITY BECOMES A CORE GOAL OF CARE

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RECOGNIZING SIGNS OF COGNITIVE OR JUDGMENT DECLINE IN DEMENTIA

- FLUCTUATING COGNITION
- INCONSISTENT OR ILLOGICAL REASONING
- PARROTING OR DEFERRING ENTIRELY TO OTHERS WITHOUT DEMONSTRATING UNDERSTANDING
- LACK OF AWARENESS ABOUT MEMORY OR JUDGMENT IMPAIRMENTS
- CONTRADICTORY OR ERRATIC EXPRESSIONS OF PREFERENCES

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ROLE OF THE CLINICIAN REGARDING MEDICAL DECISION-MAKING CAPACITY

- PRIMARY RESPONSIBILITY TO ASSESS CAPACITY AND IDENTIFY WHEN SURROGATE INPUT IS NEEDED
- DOCUMENT THOROUGHLY: WHAT WAS EXPLAINED, HOW THE PATIENT RESPONDED, AND YOUR RATIONALE
- COMMUNICATE WITH THE TEAM – INVOLVE PSYCHIATRY, ETHICS, OR LEGAL IF NEEDED
- **RESPECT AUTONOMY: DON'T ASSUME INCAPACITY BASED ON DIAGNOSIS ALONE**
 - CAPACITY IS **TASK-SPECIFIC** AND CAN **FLUCTUATE**
 - EVEN WITH DEMENTIA, MANY PATIENT CAN MAKE SOME DECISIONS
 - EARLY ASSUMPTIONS CAN UNDERMINE AUTONOMY AND TRUST

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MEDICAL DECISION-MAKING CAPACITY

- 4 NECESSARY ELEMENTS IN A CAPACITY ASSESSMENT:
 - APPRECIATION
 - RECOGNIZE SITUATION
 - UNDERSTANDING
 - COMPREHEND RELEVANT INFORMATION RELATED TO THE DECISION
 - REASONING
 - ABILITY TO WEIGH PROS AND CONS, CONSIDER OPTIONS, AND LOGICALLY PROCESS THE INFORMATION BEFORE MAKING A CHOICE
 - EXPRESSION OF CHOICE
 - COMMUNICATE DECISION CLEARLY AND CONSISTENTLY

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TRANSITION TO SURROGATE DECISION-MAKING

- WHEN CAPACITY IS LACKING:
 - CLARIFY LEGAL SURROGATE (HEALTHCARE PROXY, GUARDIAN)
 - DEFAULT SURROGATES (FAMILY OR FRIENDS)
 - DOCUMENT TRANSITION CLEARLY
 - BEGIN SHARED DECISION-MAKING PROCESS WITH SURROGATE, USING PATIENT'S KNOWN VALUES WHEN POSSIBLE

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IDEAL SURROGATE DECISION MAKER

- THE SURROGATE IS WILLING TO FOLLOW THE PATIENT'S WISHES ABOUT HEALTH CARE DECISIONS
- THE SURROGATE CAN UNDERSTAND THE MEDICAL CHOICES BEING PRESENTED
- THE SURROGATE IS GOOD AT COMMUNICATING WITH THE MEDICAL TEAM ABOUT THE PATIENT'S NEEDS AND WISHES
- THE SURROGATE IS GEOGRAPHICALLY CLOSE

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SURROGATES ARE ESSENTIAL PARTNERS IN MEDICAL DECISION MAKING

- SURROGATE DECISION MAKERS ARE FREQUENTLY UTILIZED AS PART OF THE SHARED DECISION-MAKING PROCESS IN HEALTHCARE
 - ALMOST 40% OF ADULTS ADMITTED TO A HOSPITAL LACK MEDICAL DECISION-MAKING CAPACITY
 - UP TO 90% OF ADULTS IN ICU LEVEL OF CARE LACK MEDICAL DECISION-MAKING CAPACITY
 - ~75% OF DECISIONS FOR HOSPITALIZED PATIENTS WITH LIFE THREATENING ILLNESS ARE MADE BY SURROGATES

(Raymont et al, 2004) (Sorgner et al, 2007) (Vig et al, 2007)

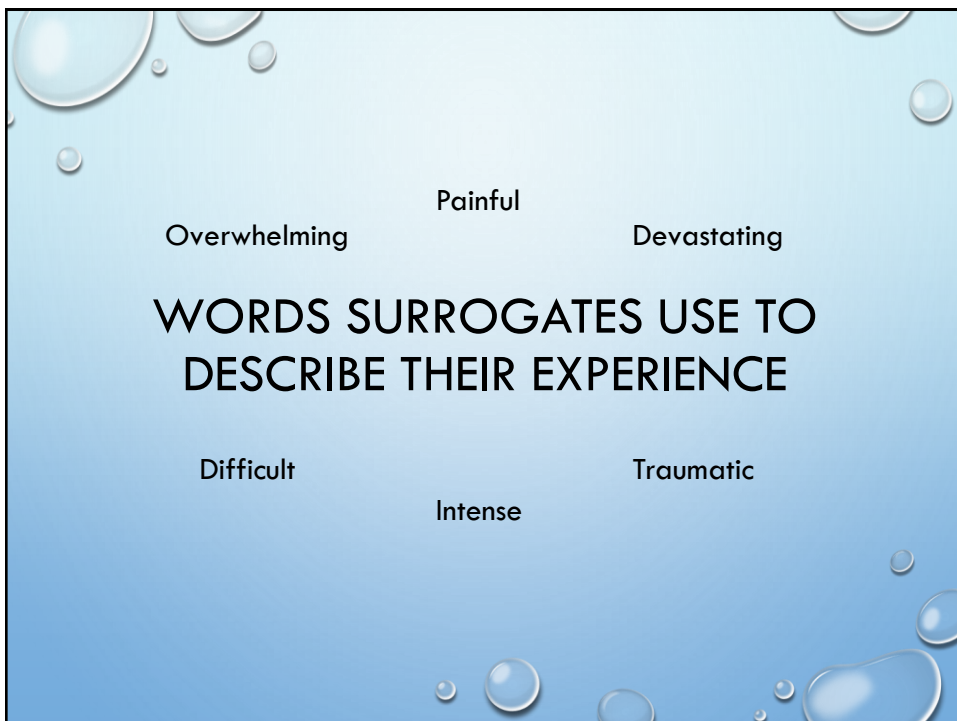
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EMOTIONAL IMPACT ON SURROGATES

- 1 IN 3 SURROGATES REPORT SIGNIFICANT EMOTIONAL BURDEN
- NEARLY 50% EXPERIENCE ANXIETY, DEPRESSION, OR PTSD SYMPTOMS
 - “I WAS TERRIFIED OF MAKING THE WRONG DECISION. I KEPT ASKING MYSELF, ‘WHAT IF THIS ISN’T WHAT HE WOULD HAVE WANTED?’ IT FELT LIKE THE WEIGHT OF HIS LIFE WAS ON MY SHOULDERS, AND I DIDN’T KNOW IF I WAS STRONG ENOUGH.”
- SPOUSE SERVING AS SURROGATE FOR A CRITICALLY ILL PATIENT

(Wendler and Rid, 2007) (Curtis and White, 2008)

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CASE STUDY

Ron is the surrogate decision maker for his 88-year-old mother who has advanced dementia, is non-verbal, and is admitted from a long-term care facility with progressive decline and poor nutritional intake

The care team is considering a feeding tube

Ron is struggling with this decision

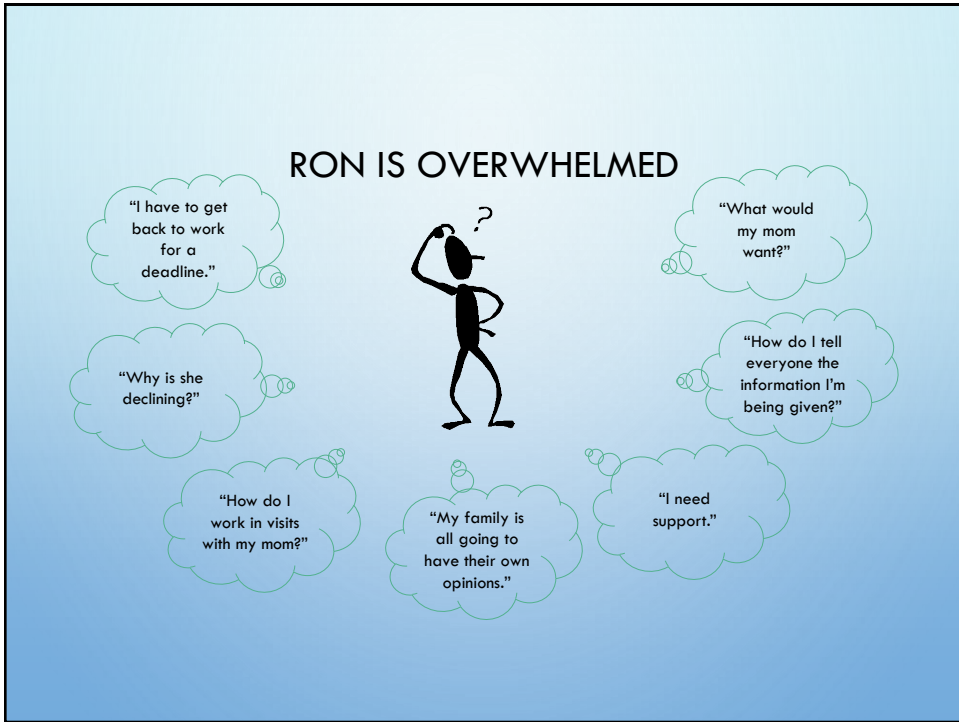
Palliative Care is consulted to be an extra layer of support for goals of care

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CASE STUDY CONTINUED

- RON SHARES:
 - HE IS AN ONLY CHILD
 - HE LIVES OUT OF STATE
 - RUNS HIS OWN BUSINESS THAT IS HIGH DEMAND IN NATURE
 - EXTENDED FAMILY IS LARGE AND LIVES IN THE AREA
- RON CONVEYS:
 - STRUGGLING WITH MAKING MEDICAL DECISIONS
 - UNCERTAINTY ABOUT WHAT HIS MOM'S WISHES ARE
 - WORRY ABOUT FAMILY DYNAMICS

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HOW CAN THE CLINICAL TEAM LIGHTEN THE WEIGHT OF SURROGATE DECISION MAKERS?

- ASSESS SURROGATE SUPPORT NEEDS
- UTILIZE THE ETHICAL CONSTRUCTS OF SURROGATE DECISION MAKING
- COMMUNICATE THERAPEUTICALLY

A 3D white figure is shown from the back, holding a large, realistic globe of the Earth on its back. The figure's arms are raised, supporting the globe. The globe shows continents and oceans in detail. The figure is standing on a plain white surface against a light blue background.

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FACTORS THAT LIGHTEN OR ADD TO THE SURROGATE'S BURDEN

✔ What Helps Surrogates	⚠ What Hampers Surrogates
✔ Prior experience making medical decisions	⚠ Competing responsibilities (e.g., work, caregiving)
✔ Effective coping strategies	⚠ Their own health challenges
✔ Emotional and logistical support systems	⚠ Family conflict or emotional attachment
✔ Knowledge of the patient's preferences	⚠ Too many conflicting clinical voices

(Vig et al. 2007)

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HOW WE LIGHTEN THE WEIGHT THROUGH SUPPORT

- ACKNOWLEDGE, LEGITIMIZE, EMPATHIZE AND SUPPORT EMOTIONAL RESPONSES
- OFFER COUNSELING SERVICES, GRIEF SUPPORT, SPIRITUAL SERVICES

(Torke et al., 2012) (Su et al., 2020)

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HOW WE LIGHTEN THE WEIGHT THROUGH ETHICAL STANDARDS

- “KNOWN WISHES” STANDARD
- SUBSTITUTED JUDGEMENT STANDARD
- BEST INTEREST STANDARD

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ETHICAL STANDARDS IN DECISION MAKING

Standard	Key Question	When to Use
Known Wishes	Did the patient leave written or verbal instructions	If advance directive or living will exist
Substituted Judgment	What would the patient choose if they could?	When values are known but not documented
Best Interest	What promotes the most benefit with the least harm	If wishes are unknown

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CASE STUDY CONTINUES

- WE SUPPORTED RON IN HIS DESIRE FOR A FAMILY CONFERENCE TO DISCUSS THE DECISION POINT AT HAND
- FAMILY EXPRESSED DIFFERING VIEWPOINTS ABOUT NEXT STEPS BASED ON PERSONAL EXPERIENCES
- FAMILY ASKED ABOUT HER ADVANCE DIRECTIVE
- ULTIMATELY, FAMILY EXPRESSED THAT IT WAS UP TO RON TO DECIDE

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COPING STRATEGIES

- RECALLING PRIOR DISCUSSIONS
- SHARING DECISION WITH FAMILY
- SPIRITUAL AND RELIGIOUS PRACTICES
- STORY-TELLING

(Schenker et al., 2012)

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HOW WE SHARE THE WEIGHT THROUGH COMMUNICATION STRATEGIES

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**"Communicating with dead people is easy.
Communicating with live people is hard!"**

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HOW WE SHARE THE WEIGHT THROUGH COMMUNICATION STRATEGIES

- AVOID MEDICAL TERMINOLOGY
- FRAME THE DECISION AROUND THE TREATMENT GOAL
RATHER THAN FOCUSING ON SPECIFICS



(Vig et al, 2009) (Weissman et al, 2009)

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HOW WE SHARE THE WEIGHT THROUGH COMMUNICATION STRATEGIES

- ELICIT VALUES FROM LOVED ONES
 - *“WHAT WOULD THEY HAVE VALUED MOST IN A SITUATION LIKE THIS?”*
- NAME THE EMOTIONAL WEIGHT
 - *“I KNOW THIS IS A HEAVY DECISION, AND THERE'S NO EASY ANSWER.”*
- AVOID INFORMATION OVERLOAD
 - FAMILIES IN CRISIS BENEFIT FROM CLEAR AND REPEATED MESSAGING
- USE “I WISH” AND “I WORRY” STATEMENTS
- UNITE AROUND A COMMON PURPOSE
 - *“LET'S WORK TOGETHER TO DO WHAT THEY WOULD WANT IF THEY COULD SPEAK FOR THEMSELVES”*

(Prochaska et al, 2015) (Schenker et al, 2012) (Weissman et al, 2009), (Vig et al, 2007)

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HOW WE SHARE THE WEIGHT THROUGH COMMUNICATION STRATEGIES

- MAKE RECOMMENDATIONS
- OFFER A TIME LIMITED TRIAL
- LISTEN
- COMMUNICATE NON-ABANDONMENT
- REASSURE THE SURROGATE ABOUT THEIR DECISION

(Prochaska et al, 2015) (Schenker et al, 2012) (Weissman et al, 2009), (Vig et al, 2007)

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HOW WE SHARE THE WEIGHT THROUGH COMMUNICATION STRATEGIES WHEN THE PATIENT'S WISHES ARE UNKNOWN

- PRIORITYZE THE PATIENT'S BEST INTERESTS
 - EMPASIZE THAT THE CARE TEAM IS COMMITTED TO DOING WHAT IS RIGHT FOR THE PATIENT
- NORMALIZE DISAGREEMENT
 - ACKNOWLEDGE THAT DIFFERING OPINIONS ARE NATURAL AND PART OF COMPASSIONATE CARE
- LEAD WITH PROFESSIONAL GUIDANCE
 - OFFER CLEAR MEDICAL RECOMMENDATIONS INSTEADOF ASKING OPEN-ENDED QUESTIONS

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CASE STUDY CONTINUES

- RON REQUESTED ADDITIONAL TIME TO DECIDE, SO A TEMPORARY NASOGASTRIC FEEDING TUBE WAS PLACED
- RON ENLISTED OPINIONS FROM THE HOSPITAL-BASED CARE TEAM
- SEVERAL MEETINGS WITH RON AND THE MEDICAL TEAM WERE NEEDED
- RON SHARED CONTINUED EMOTIONAL BURDEN OF DECIDING REGARDING A LONG-TERM FEEDING TUBE

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RESOLUTION

- RON DECIDED TO FORGO A FEEDING TUBE AND ENDORSED A HOSPICE PLAN OF CARE
- HIS MOTHER WAS DISCHARGED TO A FACILITY WITH HOSPICE SUPPORT

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RED FLAGS – WHEN SURROGATES NEED EXTRA HELP

- EXTREME GUILT OR INDECISIVENESS
- FAMILY CONFLICT OR LITIGATION
- DISAGREEMENT WITH MEDICAL TEAM
- MISUNDERSTANDING PROGNOSIS

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TOOLS TO SUPPORT SURROGATES

- DECISION AIDS
- ETHICS CONSULTATIONS
- SOCIAL WORK AND CHAPLAINCY SUPPORT
- PALLIATIVE CARE INPUT

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PALLIATIVE CARE CAN HELP...

- **COMMUNICATION AND DECISION-MAKING**
 - FACILITATES DISCUSSIONS ABOUT GOALS OF CARE AND ADVANCE DIRECTIVES EARLY IN THE DISEASE TRAJECTORY
 - HELPS FAMILIES AND SURROGATE DECISION-MAKERS UNDERSTAND THE PROGRESSION OF DEMENTIA AND MAKE INFORMED CHOICES ALIGNED WITH THE PATIENT'S VALUES
- **SUPPORT FOR CAREGIVERS**
 - OFFERS EMOTIONAL, PRACTICAL, AND SPIRITUAL SUPPORT TO CAREGIVERS
 - PROVIDES EDUCATION ON DISEASE PROGRESSION
- **END-OF-LIFE CARE**
 - SUPPORTS COMFORT AND DIGNITY IN THE FINAL STAGES OF DEMENTIA

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BUILDING A SUPPORTIVE CULTURE

- TEAM-BASED CARE: NURSES, PHYSICIANS, SOCIAL WORKERS AND CHAPLAINS
- NORMALIZE CONVERSATIONS ABOUT DYING AND CAPACITY
- ENCOURAGE EARLY ADVANCE CARE PLANNING
- OFFER PATIENT AND CAREGIVER SUPPORT RESOURCES

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RESOURCES

- NATIONAL INSTITUTE ON AGING: DEMENTIA AND CAREGIVING
 - OFFERS GUIDES ON DEMENTIA PROGRESSION, CAREGIVING STRATEGIES, AND ADVANCE CARE PLANNING
 - NIA.NIH.GOV
- THE CONVERSATION PROJECT
 - HELPS PEOPLE TALK ABOUT THEIR WISHES FOR CARE THROUGH DOWNLOADABLE GUIDES AND CONVERSATION STARTERS
 - THECONVERSATIONPROJECT.ORG
- PREPARE FOR YOUR CARE
 - STEP-BY-STEP PLANNING TOOL FOR DOCUMENTING CARE PREFERENCES AND DESIGNATING DECISION MAKERS
 - PREPAREFORYOURCARE.ORG
- CARINGINFO BY NHPCO
 - ADVANCE CARE PLANNING RESOURCES, STATE-SPECIFIC LEGAL FORMS, AND GUIDANCE ON SURROGATE ROLES
 - CARINGINFO.ORG

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RESOURCES

- GO WISH CARDS
 - A SIMPLE CARD GAME TO HELP PRIORITIZE PERSONAL VALUES IN END-OF-LIFE CARE CONVERSATIONS
 - GOWISH.ORG
- ARIADNE LABS – SERIOUS ILLNESS CARE PROGRAM
 - RESOURCES FOR CLINICIANS AND FAMILIES ON HOW TO APPROACH DIFFICULT CARE DECISIONS
 - ARIADNELABS.ORG
- CENTER TO ADVANCE PALLIATIVE CARE (CAPC)
 - PATIENT-FACING RESOURCES ON MANAGING SERIOUS ILLNESS, INCLUDING A "GET PALLIATIVE CARE" GUIDE
 - GETPALLIATIVECARE.ORG

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KEY TAKEAWAYS

- SURROGATE DECISION-MAKING CAN CAUSE LONG-TERM EMOTIONAL STRAIN
- CLINICIANS CAN EASE THIS BURDEN BY:
 - RECOGNIZING AND ADDRESSING SUPPORT NEEDS
 - APPLYING ETHICAL DECISION-MAKING FRAMEWORKS
 - USING CLEAR, COMPASSIONATE COMMUNICATION
- EMPOWERED SURROGATES = BETTER OUTCOMES FOR PATIENTS AND FAMILIES

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- “IT WAS HARD, BUT I KNEW WHAT SHE WANTED. WE HAD TALKED ABOUT IT. WHEN THE TIME CAME, I WAS CONFIDENT I WAS HONORING HER WISHES. THAT GAVE ME COMFORT—I FELT LIKE I DID RIGHT BY HER.”
— *SURROGATE FOR A MOTHER WITH ADVANCED DEMENTIA*

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THANK YOU

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FROM INDEPENDENCE TO DEPENDENCE: THE ARC OF LIFE

- 🧒 **CHILDHOOD**
 - DEPENDENT ON CAREGIVERS FOR DECISIONS AND DAILY NEEDS
- 🧑 **ADULTHOOD**
 - FULL INDEPENDENCE IN CHOICES, CAREER, HEALTH, AND FAMILY LIFE
- 🧓 **OLDER ADULTHOOD**
 - GRADUAL RETURN TO DEPENDENCE AS COGNITIVE AND PHYSICAL ABILITIES DECLINE
 - SURROGATES OFTEN STEP IN WHEN INDIVIDUALS CAN NO LONGER ADVOCATE FOR THEMSELVES