

Family Caregiving and the U.S. Health Care System

Experiences and Storytelling from Caregivers for
Individuals with a Serious Illness or Lifelong, Complex
Disability

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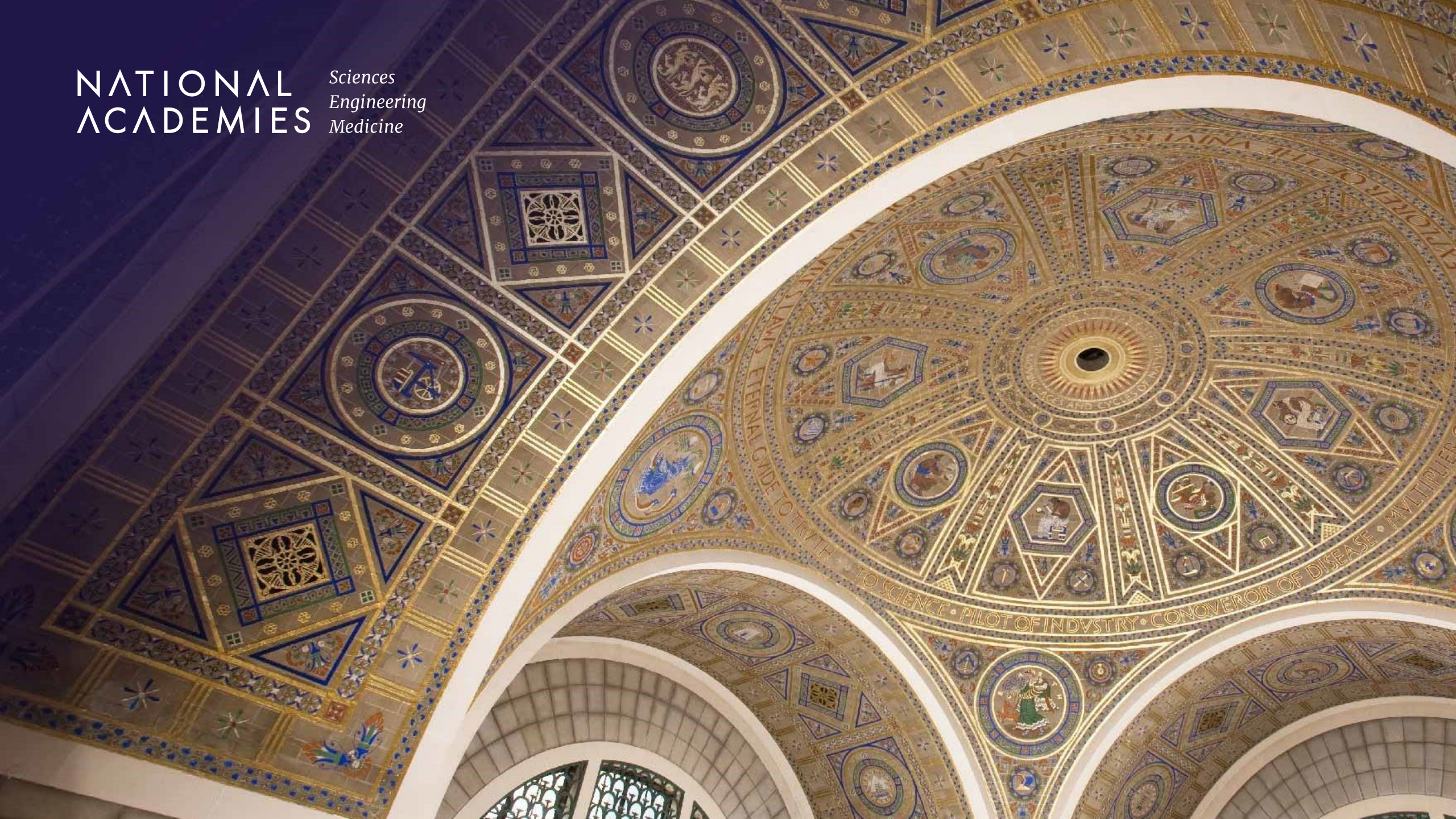






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A Chance to Rest

***Strengthening Support for Family
Caregiving: A Workshop***

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Pediatric Palliative Care Homes



January 23, 2002
Ryan and Big Brother Ethan
9 mos.



Ryan at 17 years

Daily Routine	Ethan (By Himself)	Ryan (w/ Adult)
Get Up	--	--
Chest Vest	--	15 min.
Get Dressed	3 min.	10 min.
Brush Teeth/Hair	3 min.	5 min.
Eat Breakfast	10 min.	20 min. (w/ medicines)
SCHOOL		
Afternoon Snack	5 min.	15 min.
Homework	60 min.	75 min.
Shower/Bath	10 min. – shower	45 min. Bath (w/ Lift)
Toileting	5 min.	20 min. (w/ Lift)
Dinner w/ Family	30 min.	30 min. (w/ medicines)
Evening Chest Vest	--	15 min.
Get Ready for Bed	3 min.	15 min. (AFO's, Bi-Pap)
Total Time:	129 MINUTES	265 MINUTES

+ 136 Minutes



EVERYDAY...

Not just once a week.

**2 ¼ hours a day =
OVER 820 HOURS a YEAR**

***Equivalent of
34 days a year***



Awesome
Life



Way too
short



A New Tipping Point



JOHNS HOPKINS
BLOOMBERG SCHOOL
of PUBLIC HEALTH

Thank You



ChildrensRespiteHomes.org



ChildrensRespiteHomesOfAmerica



Proud Dad

Jonathan Cottor

CEO/Founder

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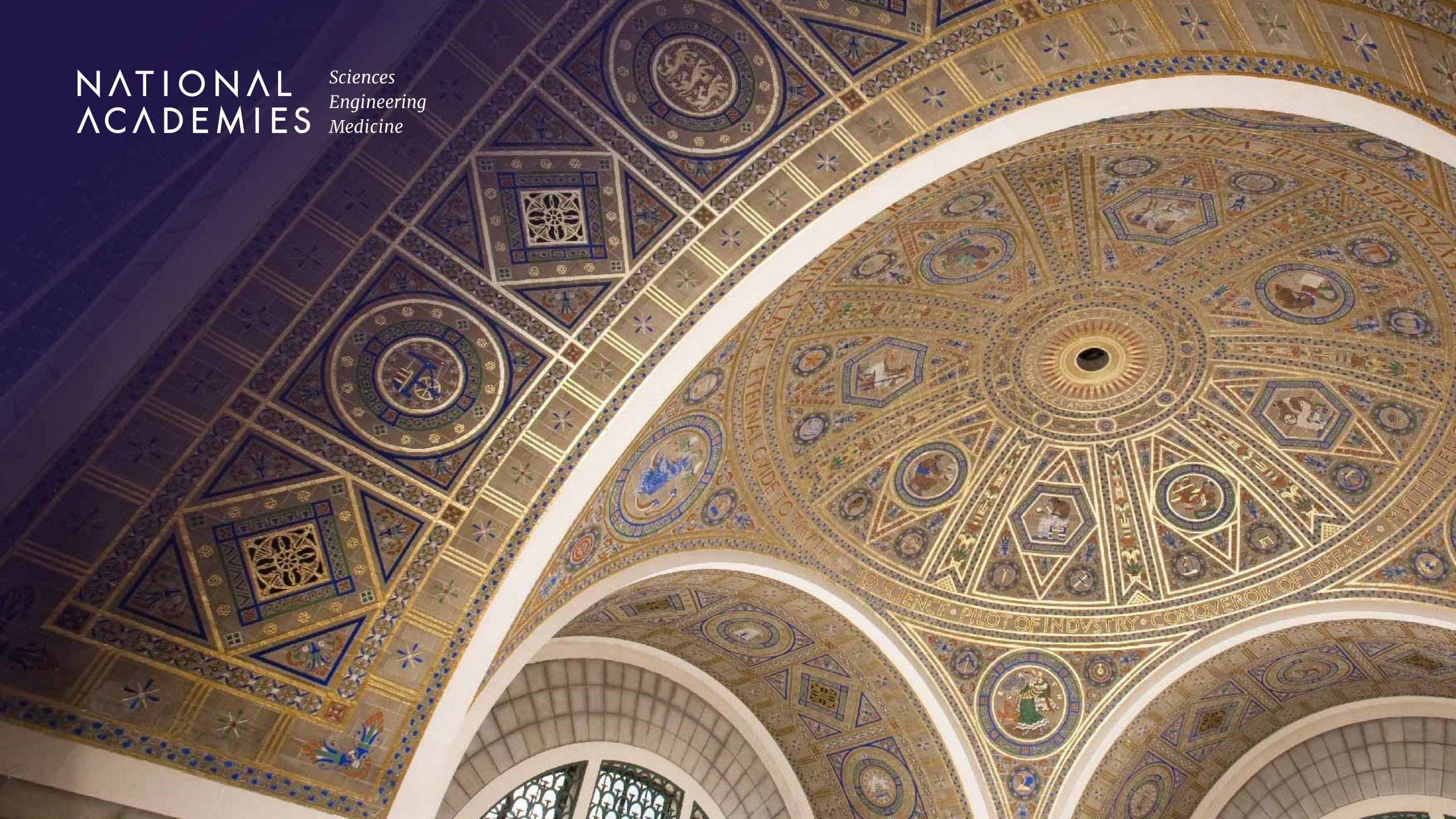
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A caregiving Story

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