Time, future, and genetics: the temporal complexity of disability

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HUMAN
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EDUCATION

Twice-told Tales: Stories about Genetic Disorders

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Overview

- Medical perspective on cystic fibrosis’s prognosis
- Prognostic messages from perspective of CF patients
- How prognosis informs life plans
- Societal structures manifesting temporal ableism
- Key disability theory on time, future, and kinship
- Recommendations for specific stakeholders

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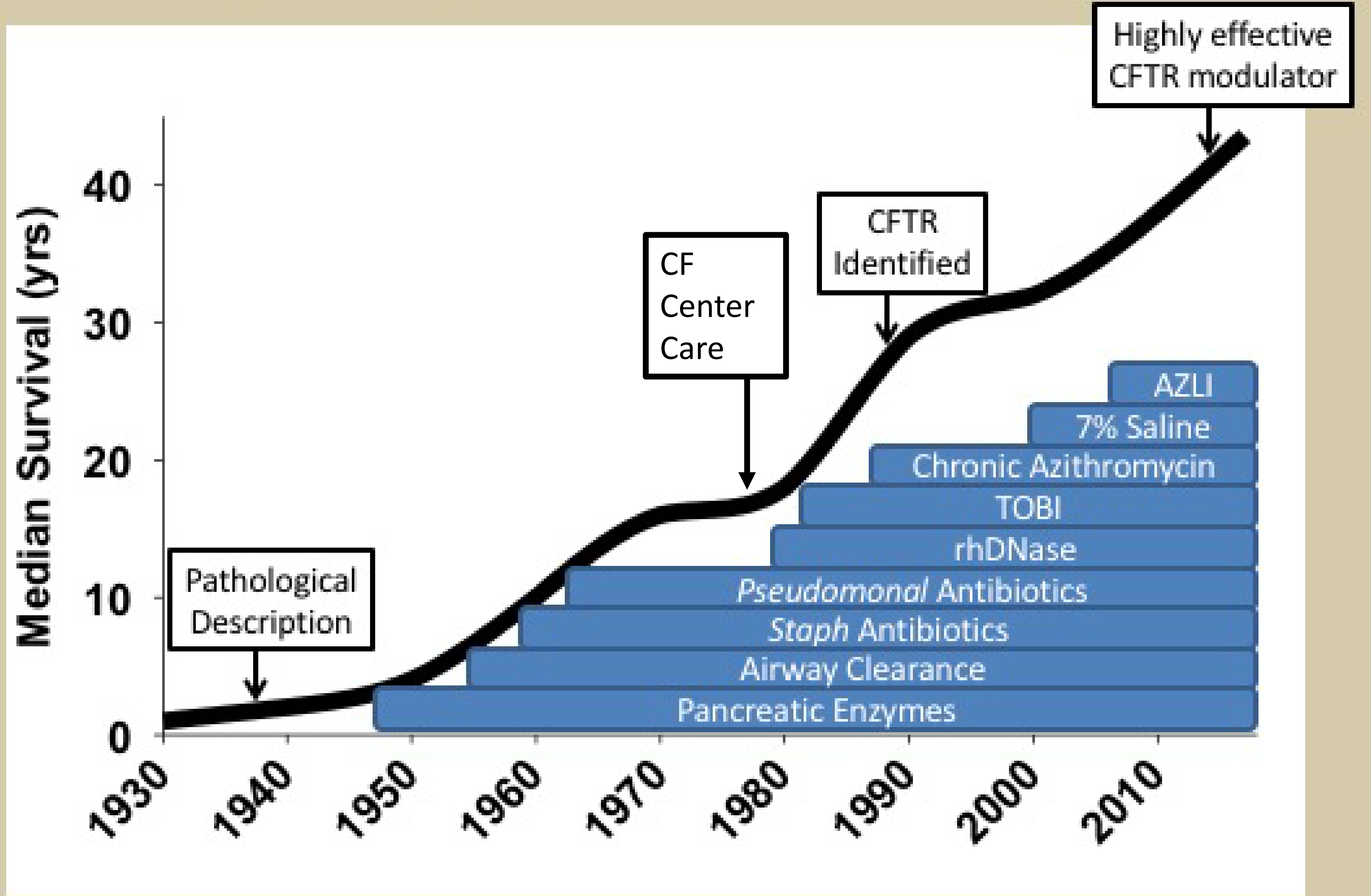
A brief history of Cystic Fibrosis

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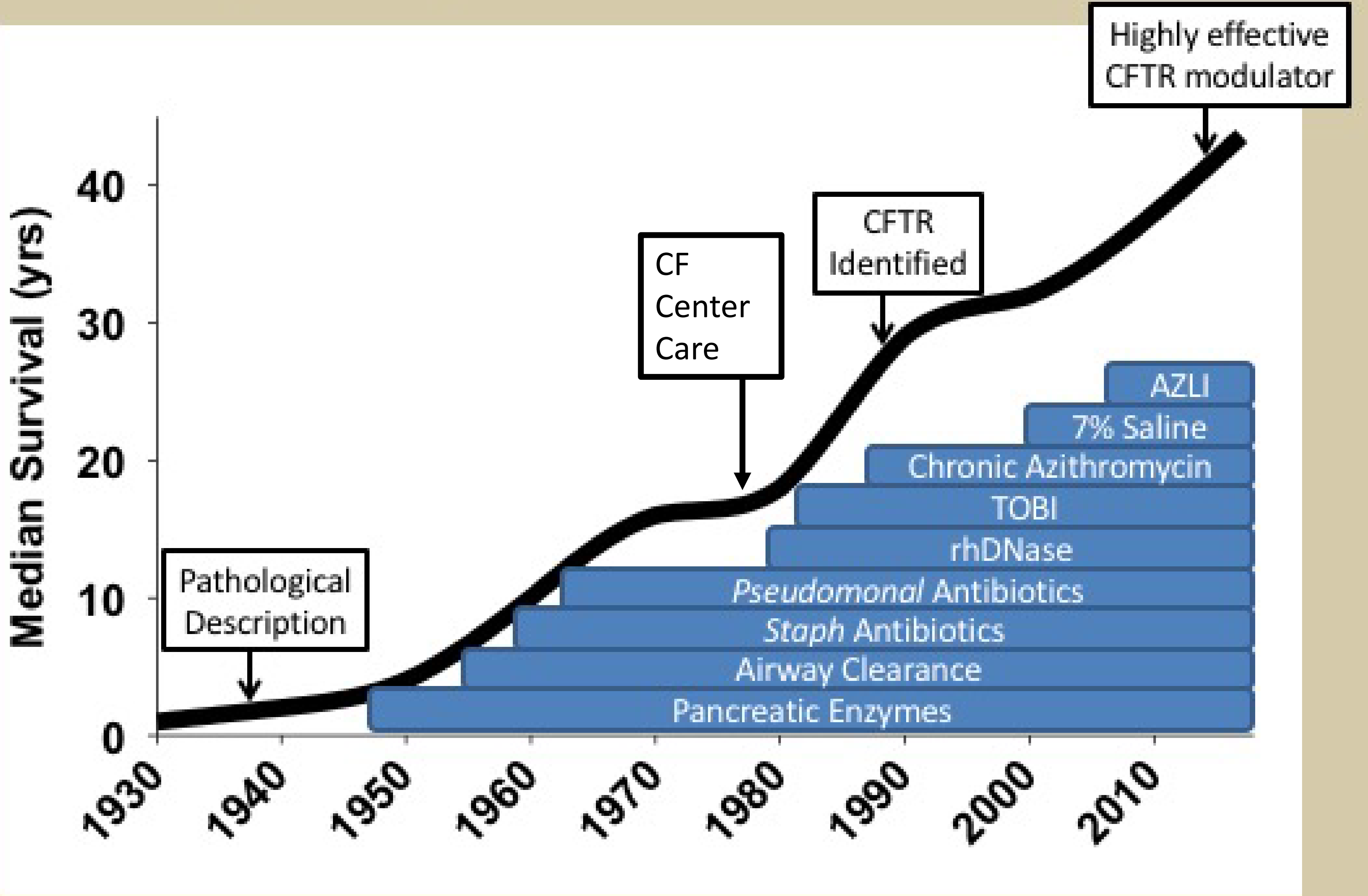
FDA NEWS RELEASE

FDA approves new breakthrough therapy for cystic fibrosis

Treatment approved for approximately 90% of patients with cystic fibrosis, many of whom had no approved therapeutic options

For Immediate Release: October 21, 2019

A brief history of Cystic Fibrosis



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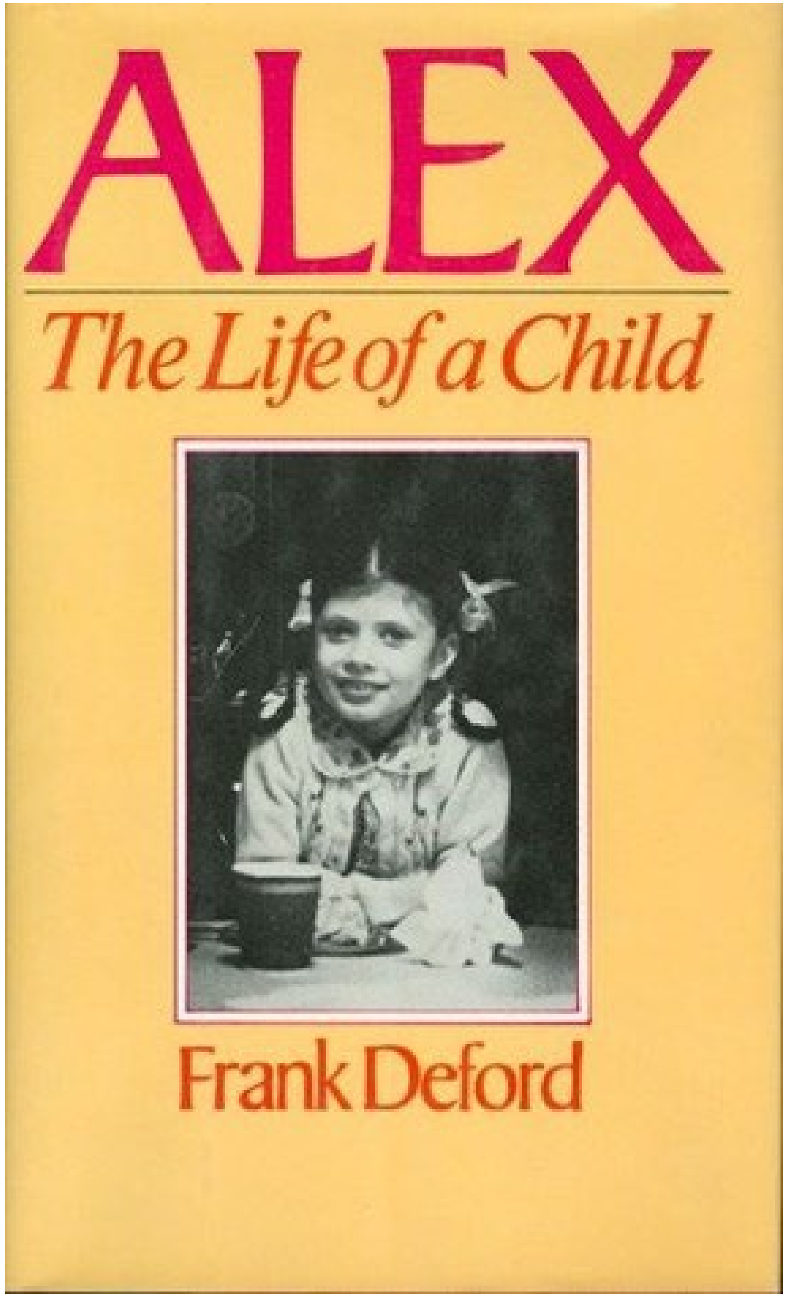
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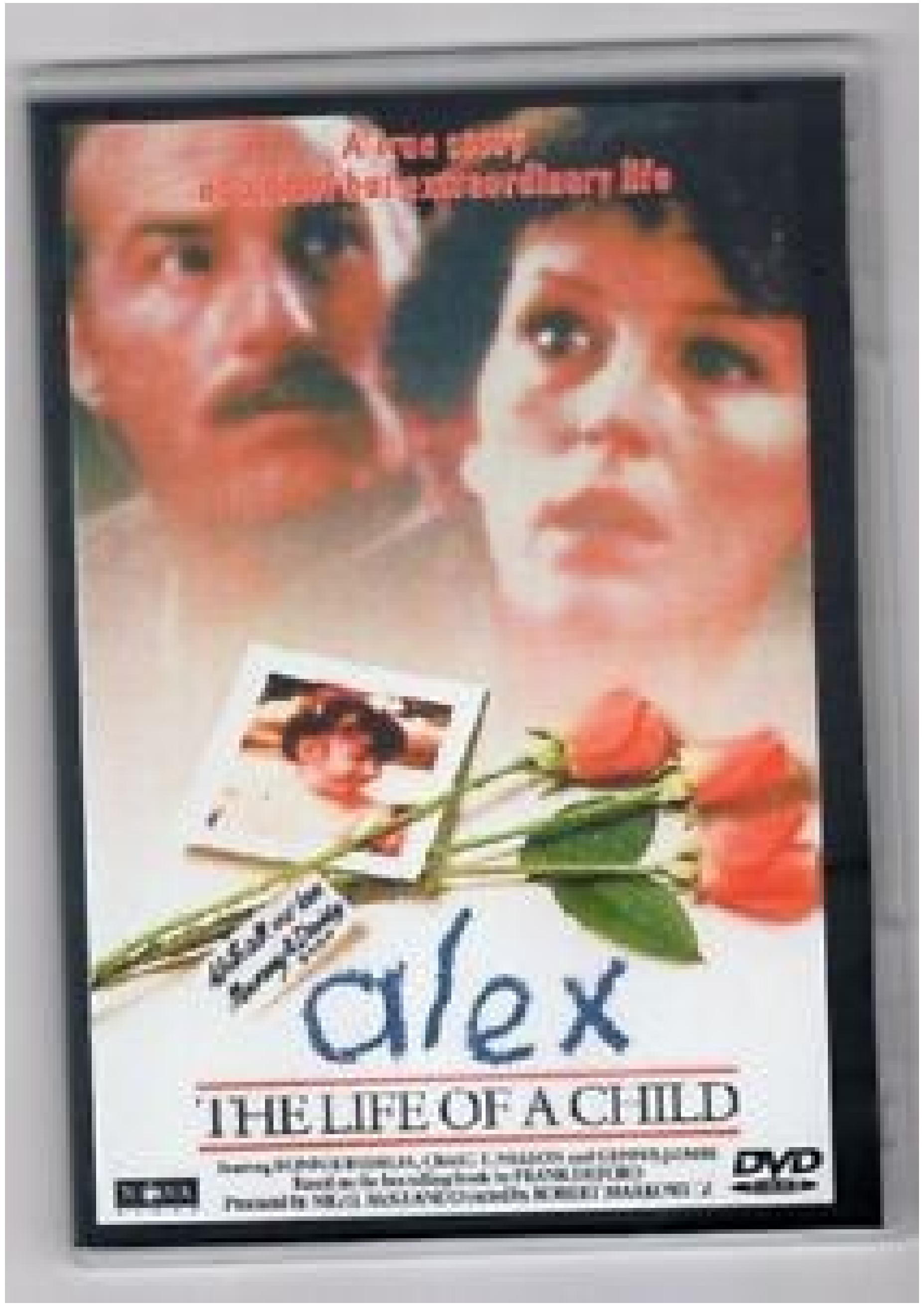
Frank Deford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THE LIFE OF A CHILD
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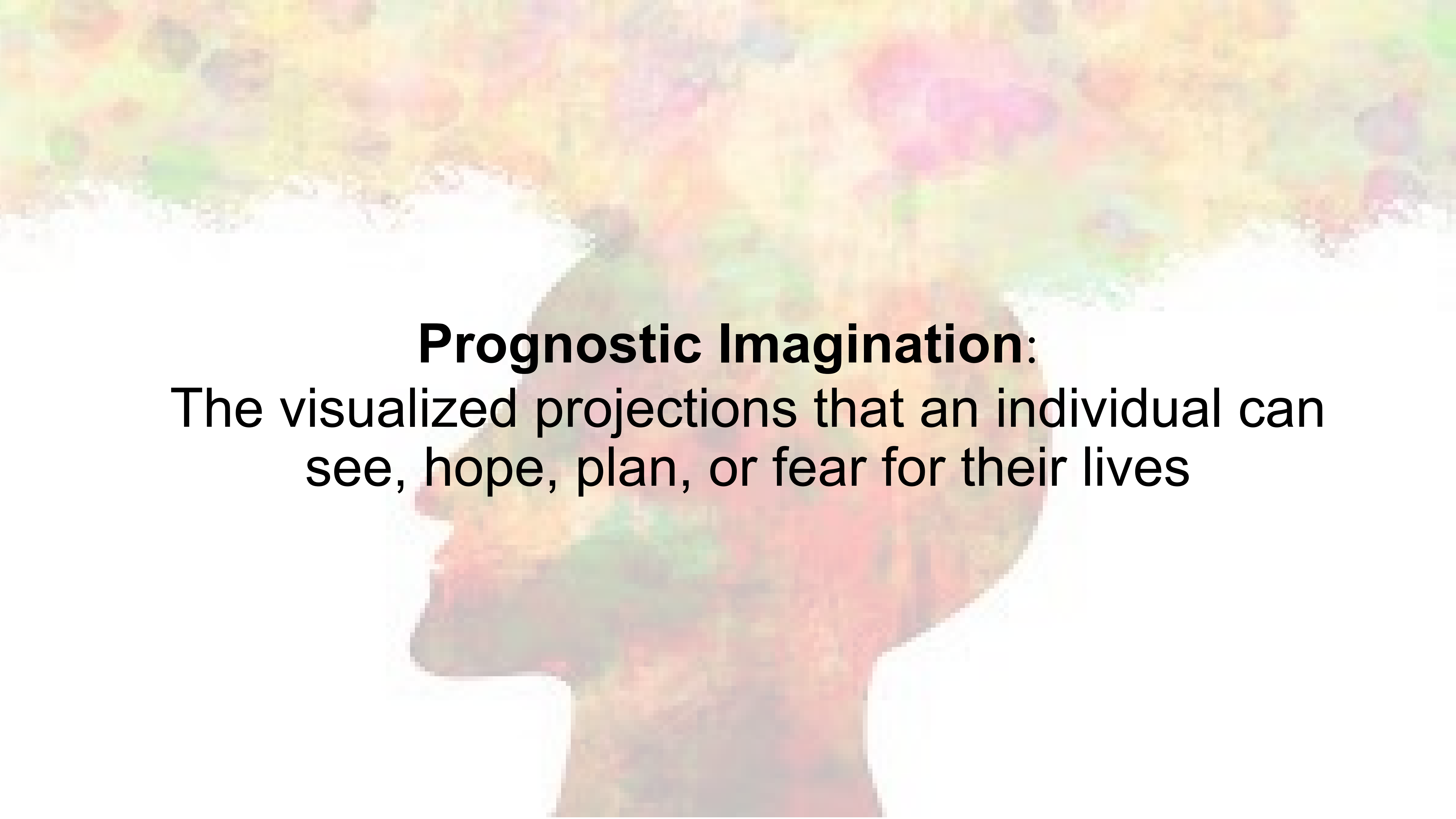
[At age six or seven] “…we were driving in the car, and I asked my mom how old people with CF live. And her whole body tensed up and she got really teary eyed. And she told me the average at that time was 25. And I definitely had that in my head growing up and I felt so compelled that I wanted to live a huge life in whatever time I had.”

-Hanna, 30s, mild FEV1

“…Like you have CF and you're how old and she just like did her treatments when we did our treatments and… it was an impactful moment because I could at that point imagine being an adult with CF. Like that is, you know, that will happen. I could go into the world and be an adult with CF.”

-Hanna, 30s, mild FEV1



Prognostic Imagination:

The visualized projections that an individual can see, hope, plan, or fear for their lives

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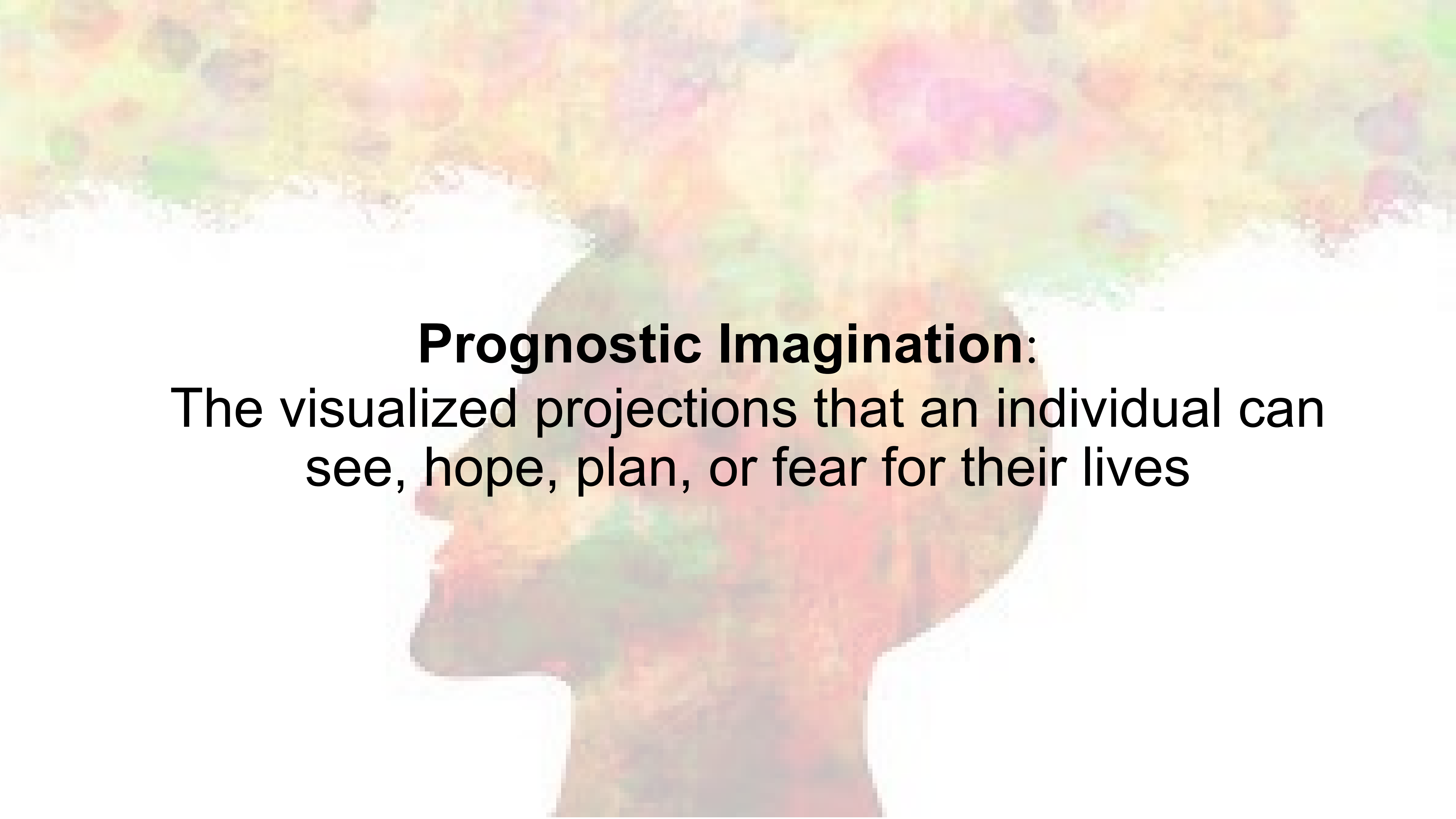

Prognostic Imagination:

The visualized projections that an individual can see, hope, plan, or fear for their lives

"… I felt so compelled that I wanted to live a huge life in whatever time I had. I went to college at 15, full time. I worked full time. I got married a week after I turned 18, moved 900 miles from home….I wanted to fit everything in…"

-Hanna, 30s, mild FEV1

“Experience is seriously important to me, you know... I've done, I've done more than most people that are healthy do.”

-John, 40s, lung transplant

“Now I'm going to turn 50 and it's like, ‘okay, have I wasted my life?’ But then I think, well I got all the medical care I needed because I was on disability. I never had to worry like other people, but I couldn't work. I have a college degree, but I couldn't work. I couldn't get married because I’d lose my benefits. Like now what do I do? Because here I am 50, and they're like, ‘you know, this probably isn't going to kill you.’ It's like, really? This is 25 years too late for me to work or get a retirement plan or whatever you do ….

-Alexandra, 40s, mild FEV1

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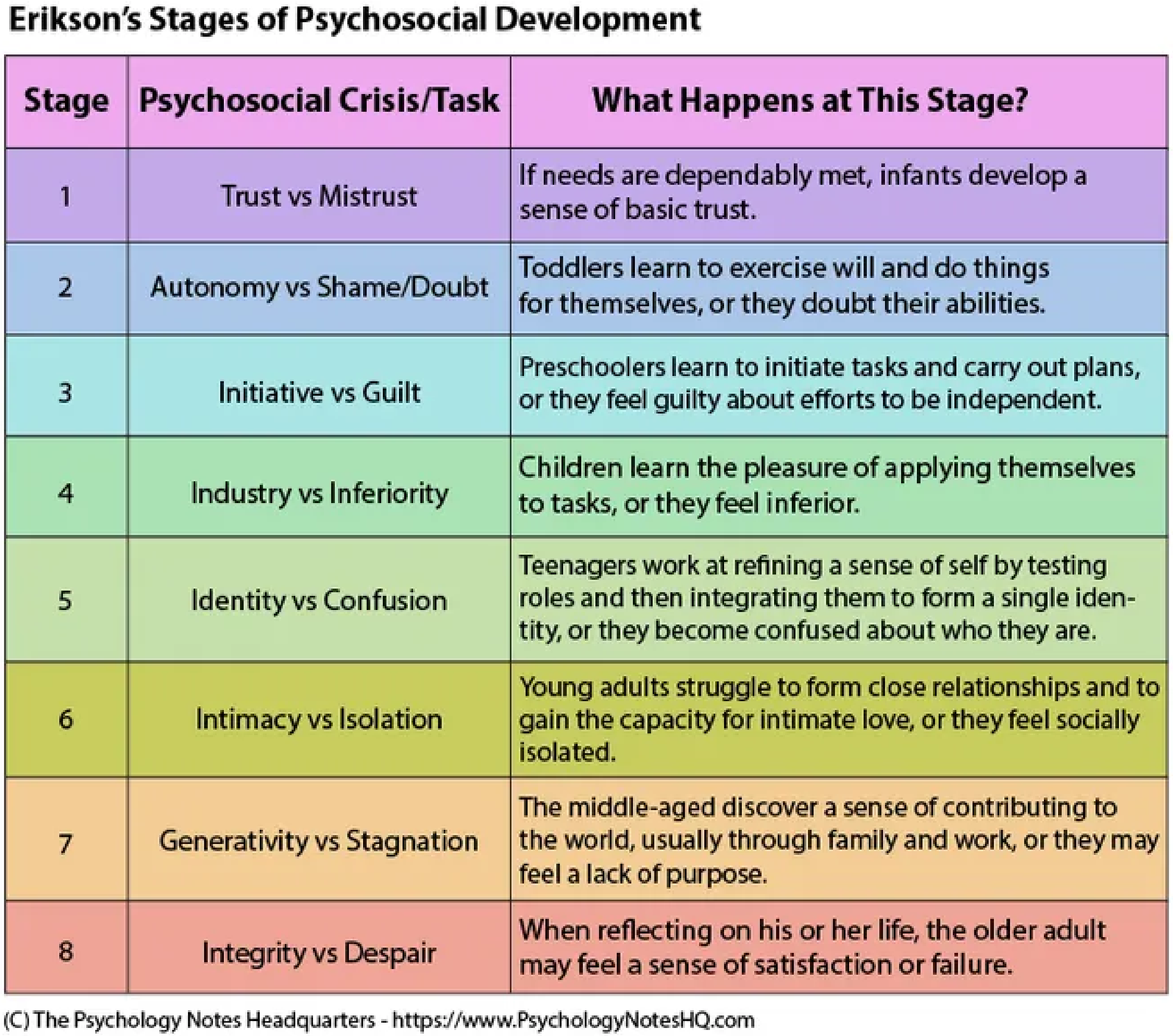

Erikson's Stages of Psychosocial Development

Stage	Psychosocial Crisis/Task	What Happens at This Stage?
1	Trust vs Mistrust	If needs are dependably met, infants develop a sense of basic trust.
2	Autonomy vs Shame/Doubt	Toddlers learn to exercise will and do things for themselves, or they doubt their abilities.
3	Initiative vs Guilt	Preschoolers learn to initiate tasks and carry out plans, or they feel guilty about efforts to be independent.
4	Industry vs Inferiority	Children learn the pleasure of applying themselves to tasks, or they feel inferior.
5	Identity vs Confusion	Teenagers work at refining a sense of self by testing roles and then integrating them to form a single identity, or they become confused about who they are.
6	Intimacy vs Isolation	Young adults struggle to form close relationships and to gain the capacity for intimate love, or they feel socially isolated.
7	Generativity vs Stagnation	The middle-aged discover a sense of contributing to the world, usually through family and work, or they may feel a lack of purpose.
8	Integrity vs Despair	When reflecting on his or her life, the older adult may feel a sense of satisfaction or failure.

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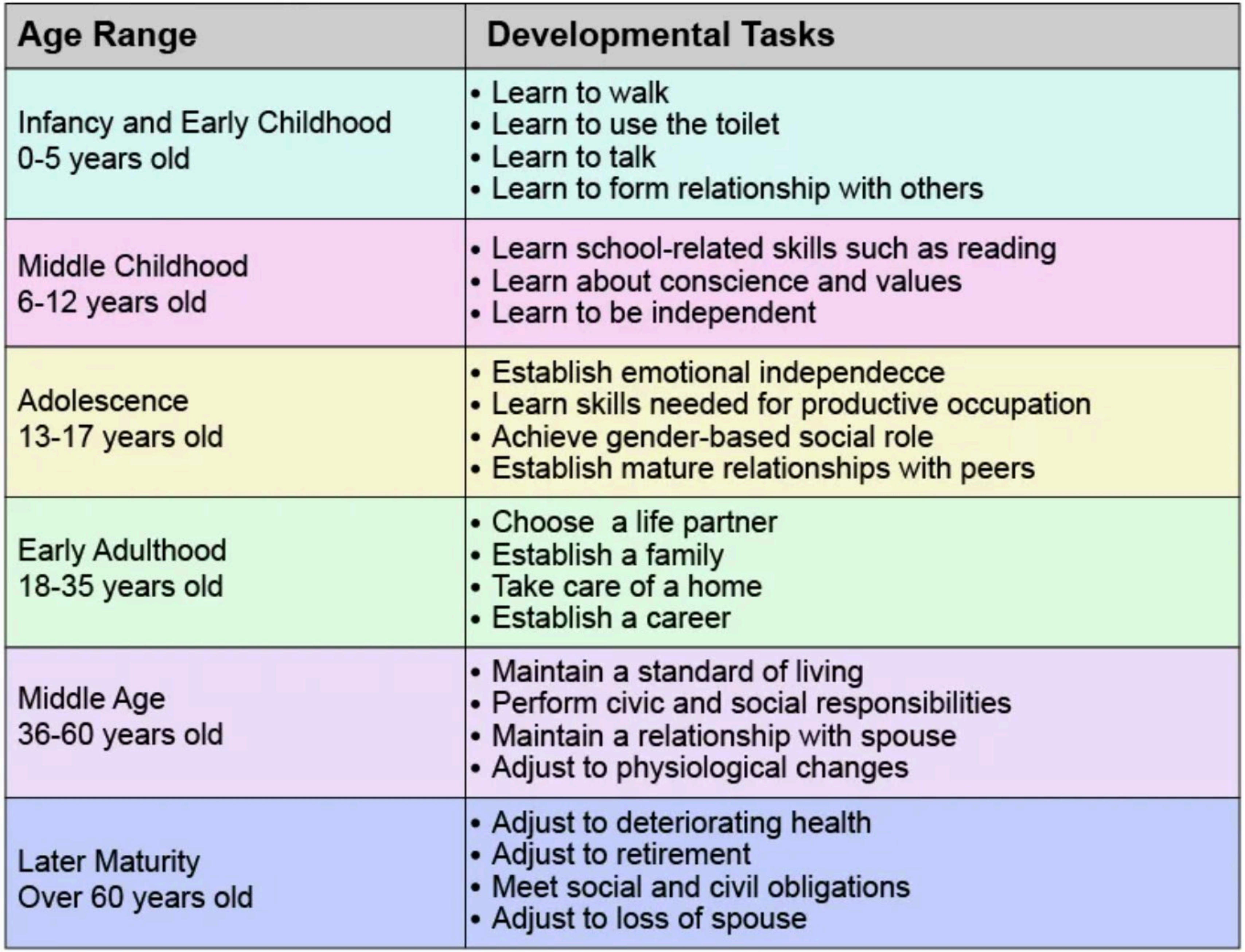
Examples of Havighurst's Developmental Tasks



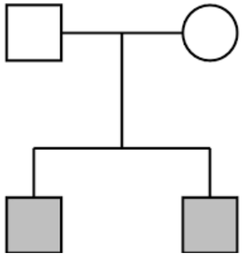
Age Range	Developmental Tasks
Infancy and Early Childhood 0-5 years old	• Learn to walk • Learn to use the toilet • Learn to talk • Learn to form relationship with others
Middle Childhood 6-12 years old	• Learn school-related skills such as reading • Learn about conscience and values • Learn to be independent
Adolescence 13-17 years old	• Establish emotional independecce • Learn skills needed for productive occupation • Achieve gender-based social role • Establish mature relationships with peers
Early Adulthood 18-35 years old	• Choose a life partner • Establish a family • Take care of a home • Establish a career
Middle Age 36-60 years old	• Maintain a standard of living • Perform civic and social responsibilities • Maintain a relationship with spouse • Adjust to physiological changes
Later Maturity Over 60 years old	• Adjust to deteriorating health • Adjust to retirement • Meet social and civil obligations • Adjust to loss of spouse

Curative Time/ Curative Imaginary

Curative time is not about any individual’s relationship with medical interventions or an individual desire for cure but rather “an understanding of disability that not only expects and assumes intervention but also cannot imagine or comprehend anything other than intervention.”

-Alison Kafer 2013, 27

The new kinship imaginary



"…As disabled kin move through the life cycle, their atypical experiences reverberate into the lives of their families in ways that reframe taken for granted assumptions. Family members find themselves recognizing and reorganizing tacit norms about familial relations and the temporality of the domestic cycle; in that process, the culturally ordered unfolding of a normative life course can no longer be assumed."

-Ginsburg and Rapp 2017, 181

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Recommendations for clinicians

- Normative expectations underly many developmental models
- Normative developmental expectations like complete independence may cause harm or alienate certain patients and families given the realities of the disease
- Adapt models and expectations to promote interdependence

Recommendations for medical providers

- Think critically about prognostic communication beyond the moment of diagnosis
- Be proactive and thoughtful in supporting prognostic communication as a child grows up
- Embrace prognostic imagination to recognize that prognostic ideas impact decisions and plans for the future

Recommendations for researchers and advocacy organizations

- Consider views and needs of community stakeholders in research design and plans to communicate findings
- For example:
  - Ask who is helped and hurt with median life expectancy data
  - Think about how to aggregate and communicate data when the disease under study has a broad phenotypic spectrum

Recommendations for social policy research and policy-makers

- Rethink disability categories that direct accommodations and eligibility for social services to reflect variable temporalities of disability
- Ensure diagnoses create options rather than constrict possibilities
- Promote policy and societal change to build accessible futures

Thank you

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- See final sides for references and image credits

Key References – Further Reading

- Baynton, D. C. (2011). 'These pushful days': time and disability in the age of eugenics. *Health and History*, *13*(2), 43-64.
- Ginsburg, F., & Rapp, R. (2017). Cripping the new normal: Making disability count. *Alter*, *11*(3), 179-192.
- Halberstam, J. (2005). *In a queer time and place: Transgender bodies, subcultural lives* (Vol. 3). NYU press.

Key References – Further Reading

- Jain, S. L. (2013). *Malignant: How cancer becomes us*. Univ of California Press.
- Kafer, A. (2013). *Feminist, queer, crip*. Indiana University Press.
- Moola, F. J., & Norman, M. E. (2011). 'Down the rabbit hole': enhancing the transition process for youth with cystic fibrosis. *Child: care, health and development*, *37*(6), 841-851.
- Moola, F. J. (2012). "This is the Best Fatal Illness That You Can Have" Contrasting and Comparing the Experiences of Parenting Youth With CF and Congenital Heart Disease. *Qualitative Health Research*, *22*(2), 212-225.

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- https://www.upmcphysicianresources.com/cme-courses/cystic-fibrosis-salty-sweat-tattoos-and-personalized-medicine
- https://cysticfibrosis2015.weebly.com/treatmentprevention.html
- https://www.psychologynoteshq.com/development-tasks/
- https://personal.utdallas.edu/~kprager/erik_erikson%202002.htm
- https://www.fda.gov/news-events/press-announcements/fda-approves-new-breakthrough-therapy-cystic-fibrosis
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