
TRYING & DYING

ARE SOME WISHES AT THE END OF LIFE BETTER?

TWO POLICY QUESTIONS UNDER DEBATE

RIGHT TO TRY

- Should terminally ill patients be allowed to take experimental drugs?

RIGHT TO DIE

- Should terminally ill patients be able to make their own end-of-life decisions, including how they die?
 - Should people receive information about planning for their end of life and medical care they may or may want?

RIGHT TO TRY – POLICY EFFORTS

REACTION TO FDA FEDERAL POLICY

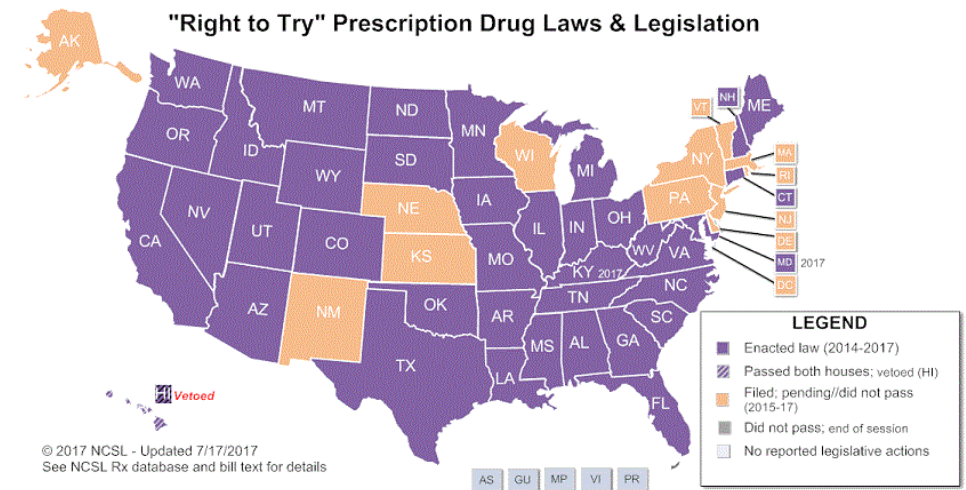
- Food and Drug Administration has exclusive control over sale and marketing of drugs
- Patient advocates and drug industry have partnered to
 - Increase funding for medical research
 - Ease regulatory burdens on drug approval process
- But some advocates believe FDA process is too slow

RIGHT TO TRY – POLICY EFFORTS

- **Administrative**
 - Compassionate or expanded use
- **Judicial**
 - US v. Rutherford
 - Abigail Alliance v. von Eschenbach
- **Legislative**

RIGHT TO TRY – POLICY EFFORTS

- State efforts
 - Roots tied back to libertarian Goldwater Institute
 - First state (Colorado) passed in 2014
 - 37th state (Maryland) passed this year
- Federal efforts
 - 21st Century Cures
 - Johnson bill passes Senate in August 2017



RIGHT TO TRY PROPOSALS

Model State Proposal

- Patient must be terminally ill
 - Considered all FDA-approved options
- Does not create a mandate on drug maker to provide
 - Allows drug maker to recoup costs
- Does not create a mandate on insurer
- Immunity for drug maker and administering physician

Johnson bill (S. 204) as passed

- Patient must have a life-threatening condition
- Patient can request directly from drug maker, but bill does not displace compassionate use
- Prohibits FDA from using clinical outcome from experimental drug
- Immunity for drug maker and administering physician
- No new entitlement or mandate

RIGHT TO DIE – POLICY EFFORTS

■ Administrative

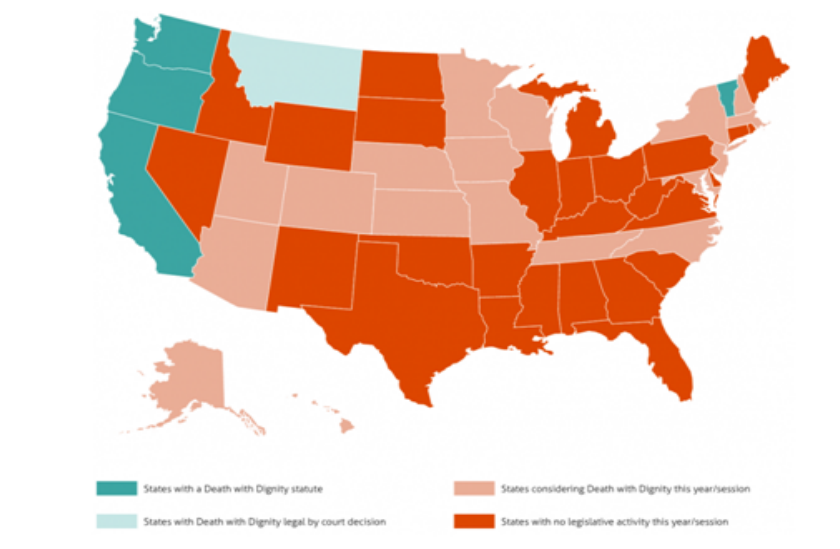
- Federal: allow for advance care planning conversations

■ Judicial

- Washington v. Glucksberg: no right to die in the Constitution
- Gonzalez v. Oregon: no federal preemption of state law

■ Legislative

- Federal: Patient Self-Determination Act, Affordable Care Act
- States: handful have laws or judicial decisions on point



POLITICAL LESSONS: WHAT TO LEARN FROM RIGHT TO TRY?

Differences

- Right to try: hope for miracle, no consequences
 - Right to die: finality
- Right to try: asking for others' property
 - Right to die: individual choices, not affecting other property

Similarities

- Respect for individual autonomy
 - But CA: right to try proponents try to parallel right to die
 - Assertion that there is a general right to die
- Increased information about ACP, options parallels 21st Century Cures on information about clinical trials, understanding compassionate use