

# Rare Disease Patient Journey

Every person's experience with a rare disease is unique, but there are many things that people may have in common. This graphic represents some of those commonalities within the different potential phases or stages of life with a rare condition.



## Now What?

- Coping with a rare diagnosis
- Learning about disease management
- Understanding potential clinical trials
- Navigating costs and insurance
- Explaining a diagnosis to friends, family
- Improving communication skills with healthcare providers



## Education

- Managing misdiagnoses, misinformation, no information
- Accessing appropriate healthcare
- Finding available services or programs
  - Individualized Education Program (IEP)
  - 504 Plan
- Participating in social activities



## Future

- Contributing to advocacy: legislation, policy, support
- Preparing financially
- Contributing to research/scientific advances
- Imagining a potentially different future
- Creating a patient advocacy organization



## Transitions

- Becoming a teenager/young adult
- Entering college
- Finding a job
- Beginning relationships/families
- Medical transitions
  - Sudden or acute changes
  - Long-term, progressive change



## Ownership

- Making and coping with lifestyle changes
- Managing family dynamics
- Building a support network
- Educating healthcare providers



## Impact on Daily Living

- Caring for someone with a rare disease
- Addressing and understanding:
  - Mental/emotional health
  - Physical health
  - Social health



## What's Wrong?

- Seeking answers
- Pursuing a diagnosis
- Finding the right healthcare providers

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