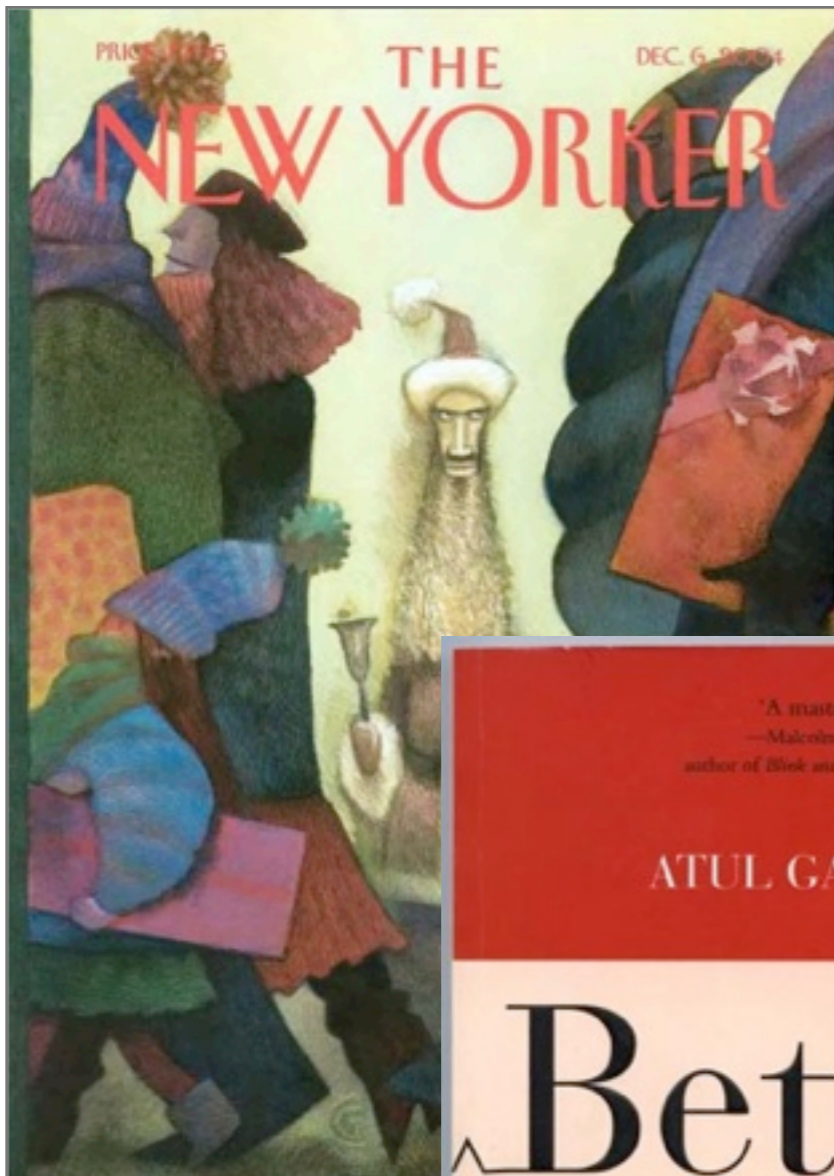


Reframing Health

Rajiv Mehta

Healthcare Unbound, July 2010, San Diego, CA



ANNALS OF MEDICINE

THE BELL CURVE

What happens when patients find out how good their doctors really are?

BY ATUL GAWANDE

Every illness is a story, and Annie Page's began with the kinds of small, unexceptional details that mean nothing until seen in hindsight. Like the fact that, when she was a baby, her father sometimes called her Little Potato Chip, because her skin tasted salty when he kissed her. Or that Annie's mother noticed that her breathing was sometimes a little wheezy, though the pediatrician heard nothing through his stethoscope.

The detail that finally mattered was Annie's size. For a while, Annie's frenched petiteness seemed to be just a family trait. Her sister, Lauryn, four years older, had always been at the bottom end of the pediatrician's growth chart for girls her age. By the time Annie was three years old, however, she had fallen off the chart. She stood an acceptable thirty-four inches tall but weighed only twenty-three pounds—less than ninety-

percent of girls her age. A technician then measured the concentration of chloride in the pad.

Over the phone, the doctor told Honor that her daughter's chloride level was far higher than normal. Honor is a hospital pharmacist, and she had come across children with abnormal results like this. "All I knew was that it meant she was going to die," she said quietly when I visited the Pages' home, in the Cincinnati suburb of Loveland. The test showed that Annie had cystic fibrosis.

Cystic fibrosis is a genetic disease. Only a thousand American children per year are diagnosed as having it. Some ten million people in the United States carry the defective gene, but the disorder is recessive: a child will develop the condition only if both parents are carriers and both pass on a copy. The gene—which was

identified in 1989, sitting out on the long arm of chromosome No. 7—prevents a protein that interferes with the body's ability to manage chloride. The protein also makes sweat from people salty. (Salt is sodium chloride.) The chloride defect thickens mucus throughout the body, mainly in the lungs and pancreas.

In the lungs, the mucus blocks the flow of air, making it difficult to breathe. In the pancreas, the mucus blocks the flow of digestive enzymes, making a child unable to absorb food. This was the case with Annie. She had all but stopped growing, and her lungs, however, were still on the verge of collapse. Thickened mucus fills the small airways and shrinks lung capacity. Over time, the disease leaves a child with the lungs of just one functioning lung, a lung. Then none at all.

The overwhelming thought in the mind of Honor and Don Page was to get to Children's Cincinnati Hospital, among the most pediatric hospitals in the country, where Albert Sabin invented the polio vaccine. The chapter on

cystic fibrosis in the "Nelson Textbook of Pediatrics"—the bible of the specialty—was written by one of the hospital's pediatricians. The Pages called and were given an appointment for the next morning.

"We were there for hours, meeting with all the different members of the team," Honor recalled. "They took Annie's blood pressure, measured her oxygen saturation, did some other tests. Then they put us in a room, and the pediatrician sat down with us. He was very kind, but frank, too. He said, 'Do you understand it's a genetic disease? That it's nothing you did, nothing you can catch?' He told us the median survival for patients was thirty years. In Annie's lifetime, he said, we could see that go to forty. For him, he was sharing a great accomplishment in CF care. And the news was better than our worst fears. But only forty! That's not what we wanted to hear."

The team members reviewed the treatments. The Pages were told that they would have to give Annie pancreatic-enzyme pills with the first bite of every meal. They would have to give her supplemental vitamins. They also had to add calories wherever they could—putting tablespoons of butter on everything, giving her ice cream whenever she wanted, and then putting chocolate sauce on it.

A respiratory therapist explained that they would need to do manual chest therapy at least twice a day, half-hour sessions in which they would strike—"percuss"—their daughter's torso with a cupped hand at each of fourteen specific locations on the front, back, and sides in order to loosen the thick secretions and help her to cough them up. They were given prescriptions for inhaled medicines. The doctor told them that Annie would need to come back once every three months for extended checkups. And then they went home to start their new life. They had been told almost everything they needed to know in order to give Annie



Doctors like to think they're doing their job as well as it can be done. But when you measure their results the spread is wide.

her best chance to live as long as possible.

The one thing that the clinicians failed to tell them, however, was that Cincinnati Children's was not, as the Pages supposed, among the country's best centers for children with cystic fibrosis. According to data from that year, it was, at best, an average program. This was no small matter. In 1997, patients at an average center were living to be just over thirty years old; patients at the top-center typically lived to be forty-six. By some measures, Cincinnati was well below average. The best predictor of a CF patient's life expectancy is his or her lung

function. At Cincinnati, lung function for patients under the age of twelve—children like Annie—was in the bottom twenty-five per cent of the country's CF patients. And the doctors there knew it.

It used to be assumed that differences among hospitals or doctors in a particular specialty were generally insignificant. If you plotted a graph showing the results of all the centers treating cystic fibrosis—or any other disease, for that matter—people expected that the curve would look something like a shark fin, with most places clustered around the very best out-

comes. But the evidence has begun to indicate otherwise. What you tend to find is a bell curve: a handful of teams with disturbingly poor outcomes for their patients, a handful with remarkably good results, and a great undistinguished middle.

In ordinary hernia operations, the chances of recurrence are one in ten for surgeons at the unhappy end of the spectrum, one in twenty for those in the middle majority, and under one in five hundred for a handful. A Scottish study of patients with treatable colon cancer found that the ten-year survival rate ranged from a high of sixty-three

"A masterpiece"
—Malcolm Gladwell,
author of *Blink* and *The Tipping Point*



ATUL GAWANDE

Better

A Surgeon's
Notes on
Performance

Patient's perspective



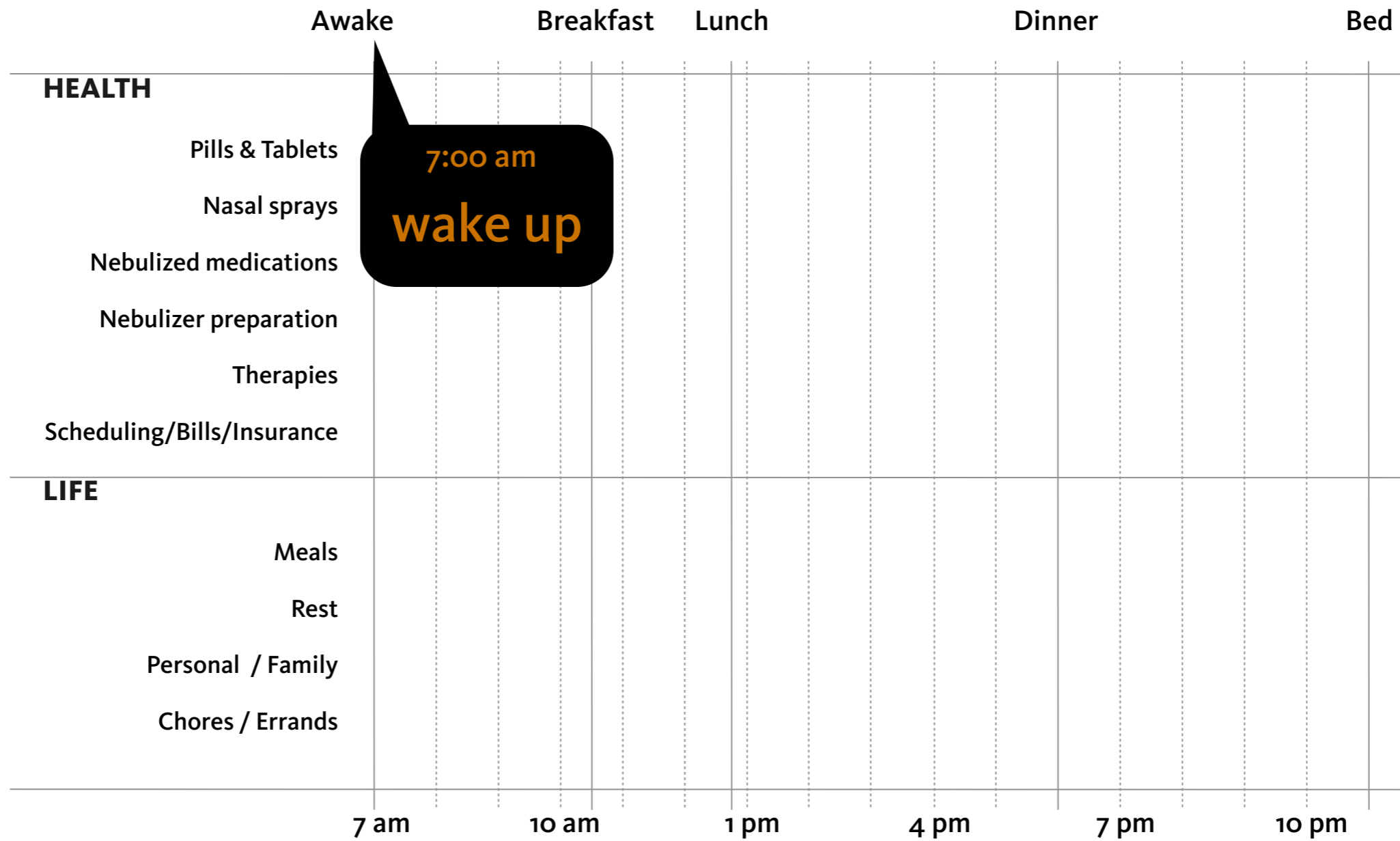
Day-in-the-Life

of a woman with Cystic Fibrosis
age 31, married, 2-year-old son

Cystic Fibrosis

woman; age 31; married; 2 yr old son

- Legend**
- Health related
 - Other

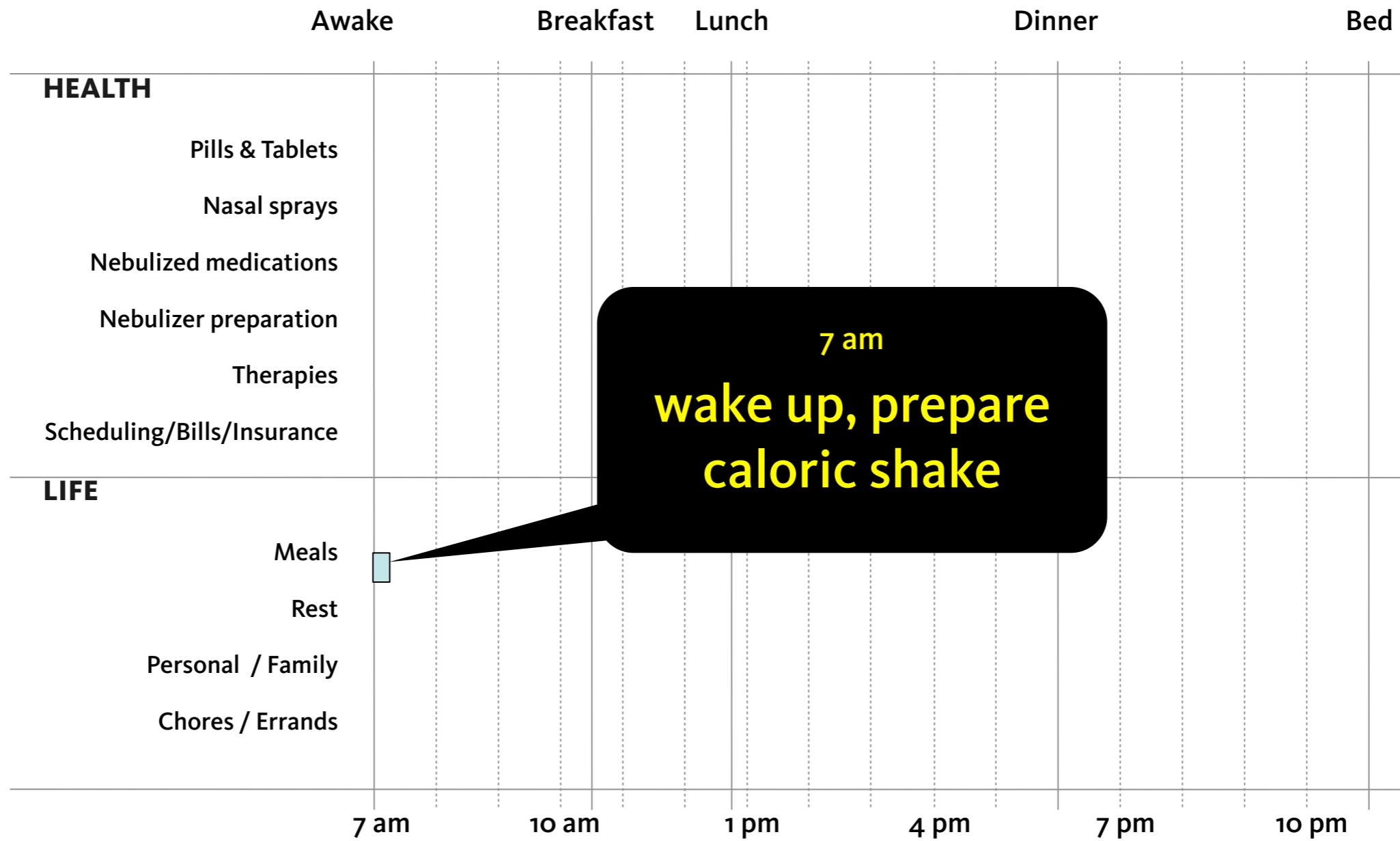


Cystic Fibrosis

woman; age 31; married; 2 yr old son

Legend

- Health related
- Other

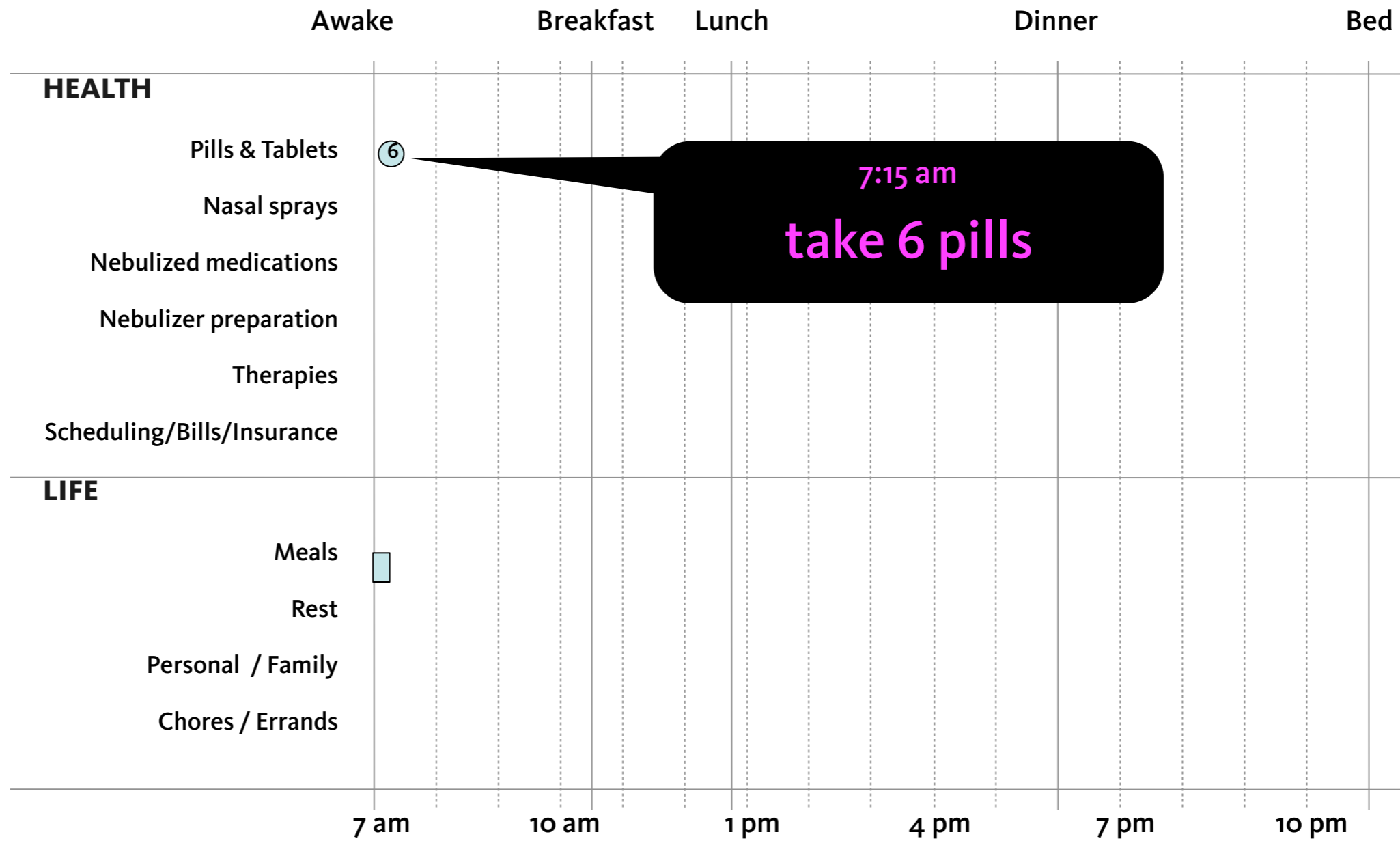


Cystic Fibrosis

woman; age 31; married; 2 yr old son

Legend

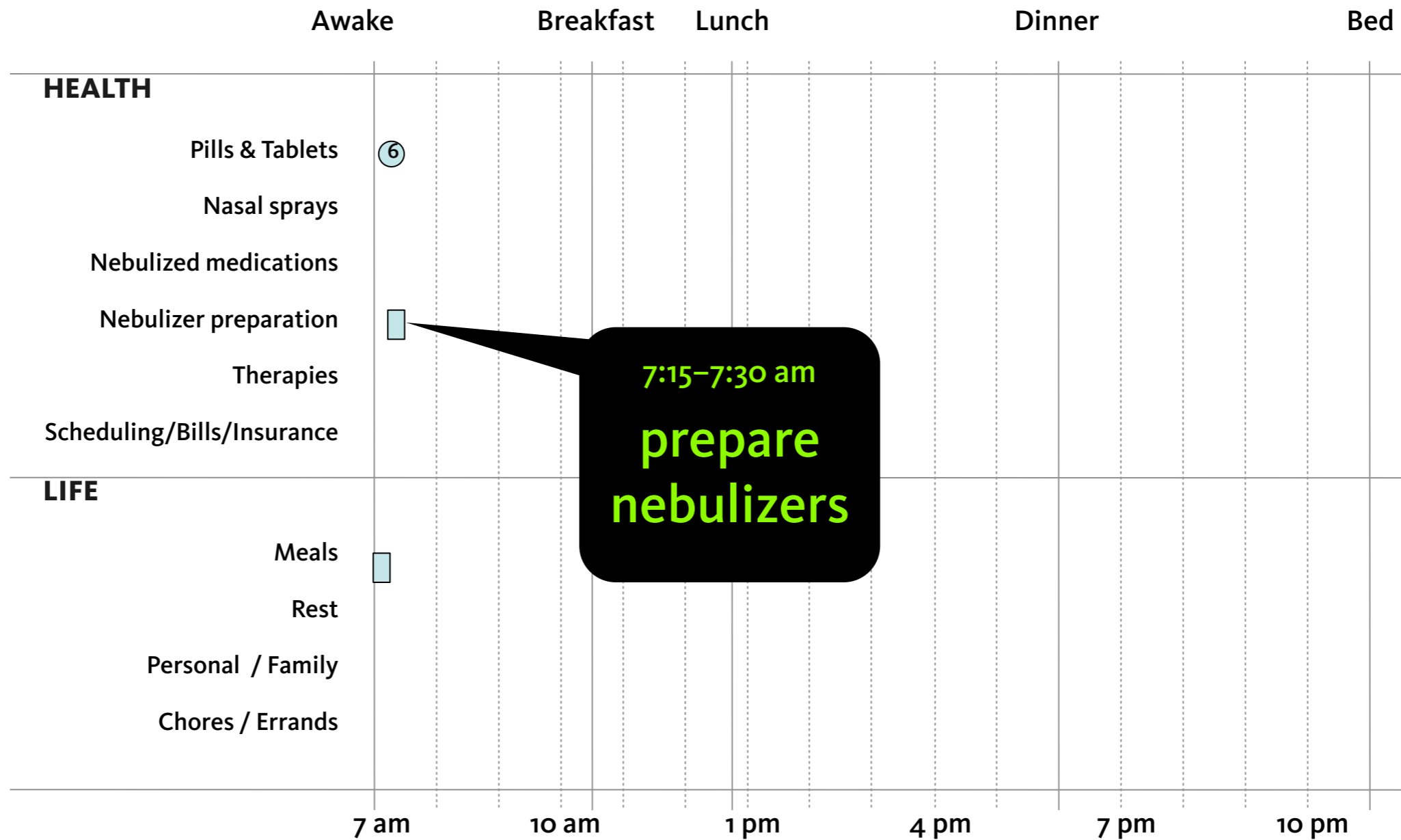
- Health related
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Cystic Fibrosis

woman; age 31; married; 2 yr old son

- Legend**
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 - Other

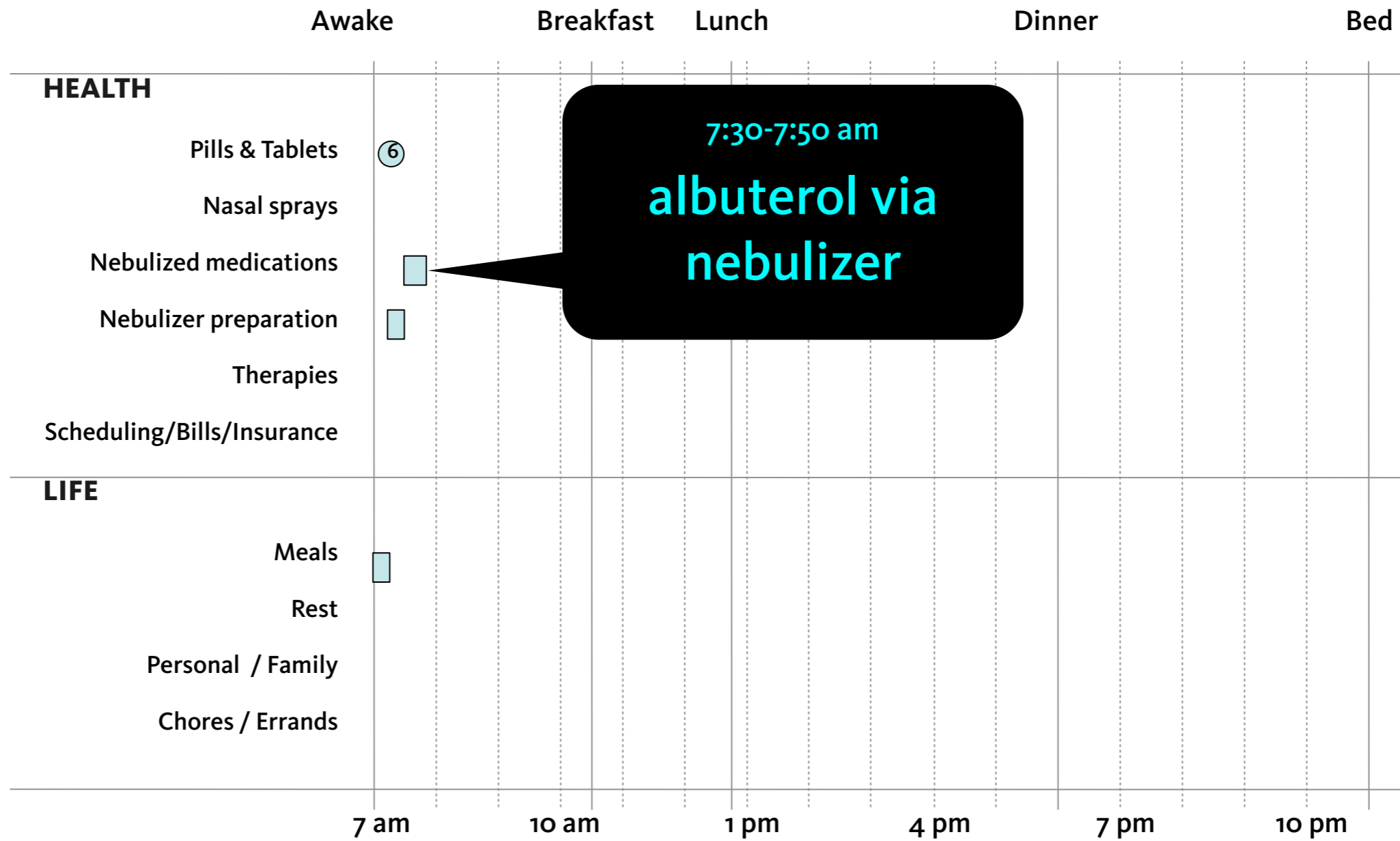


Cystic Fibrosis

woman; age 31; married; 2 yr old son

Legend

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- Other

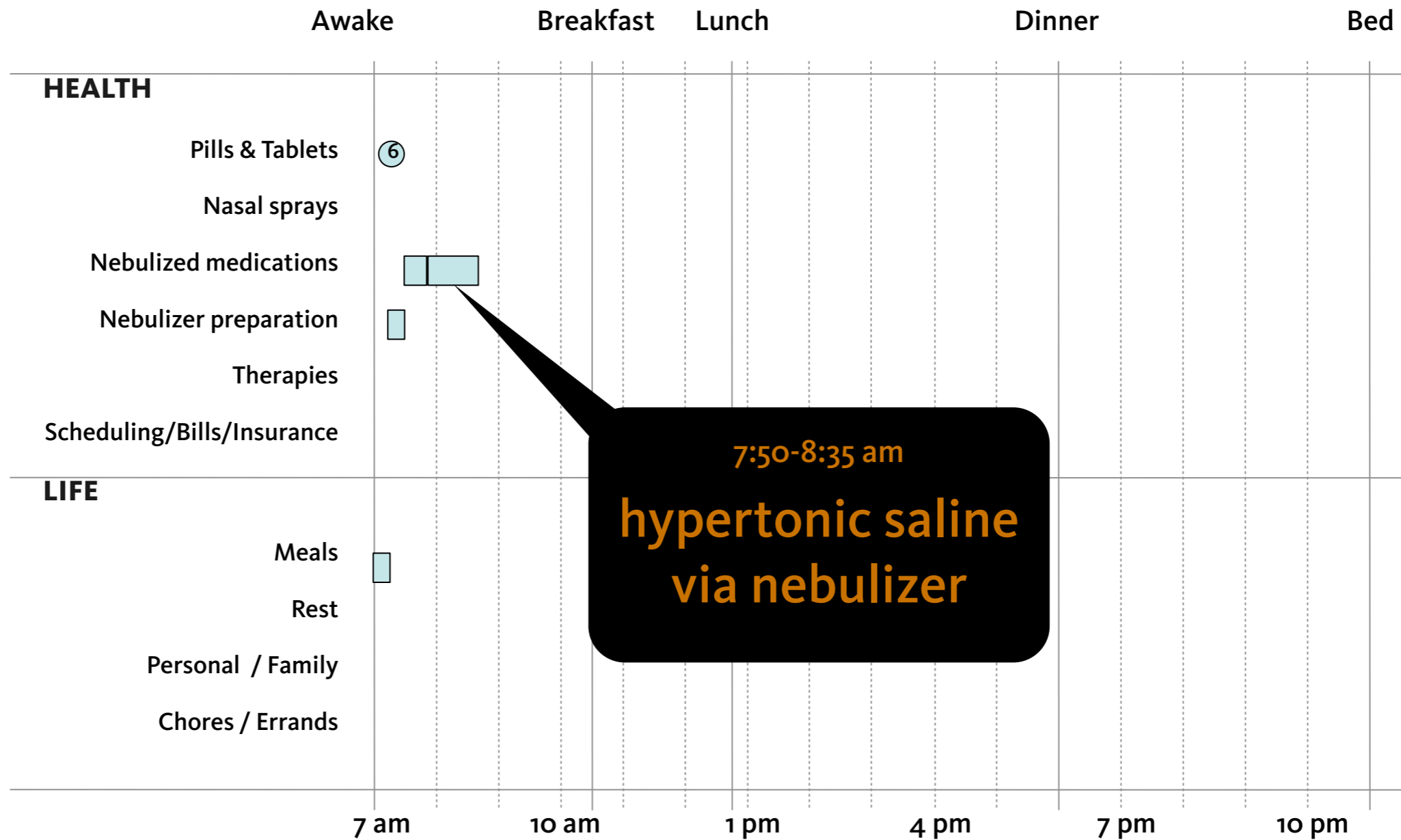


Cystic Fibrosis

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Legend

- Health related
- Other

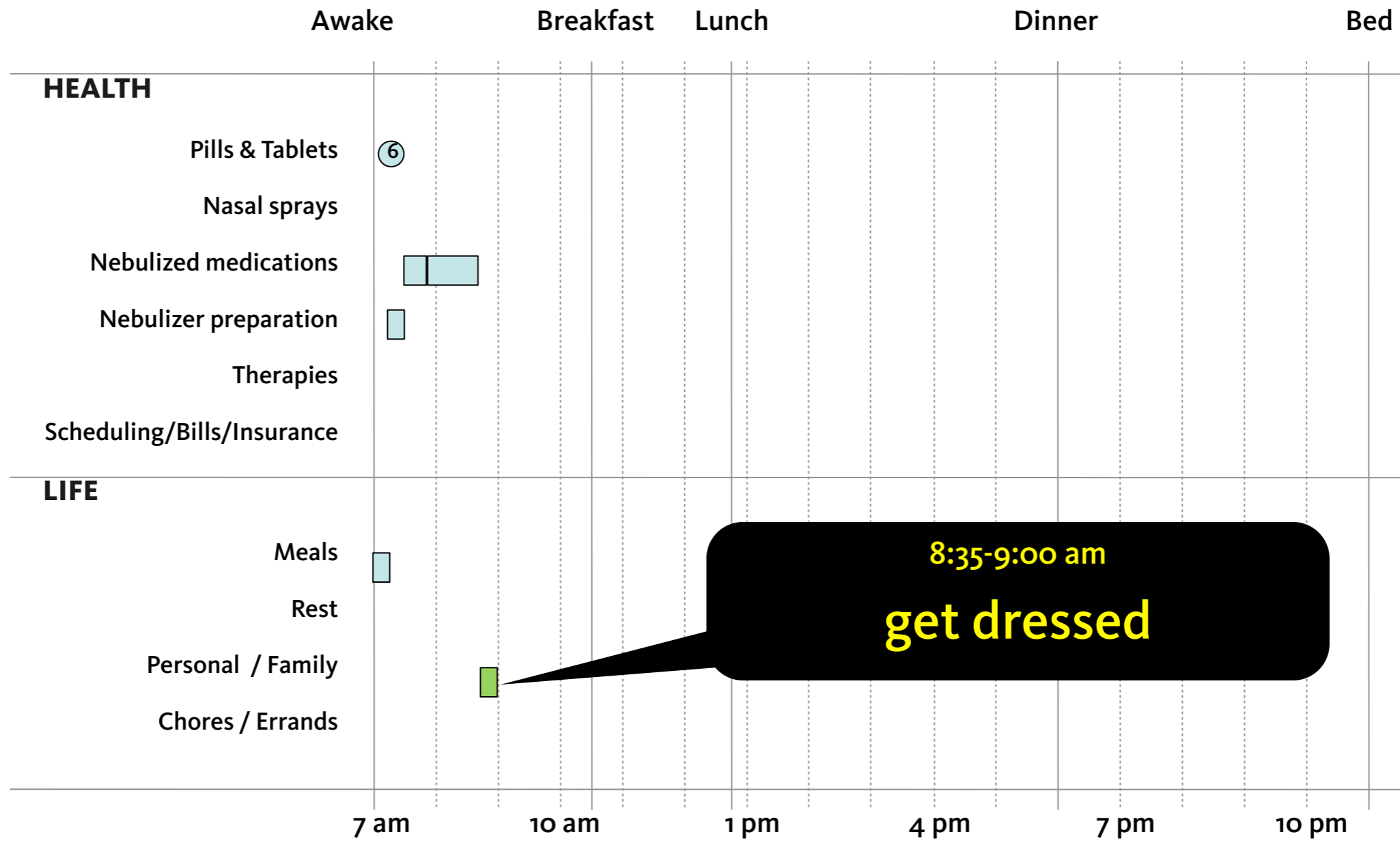


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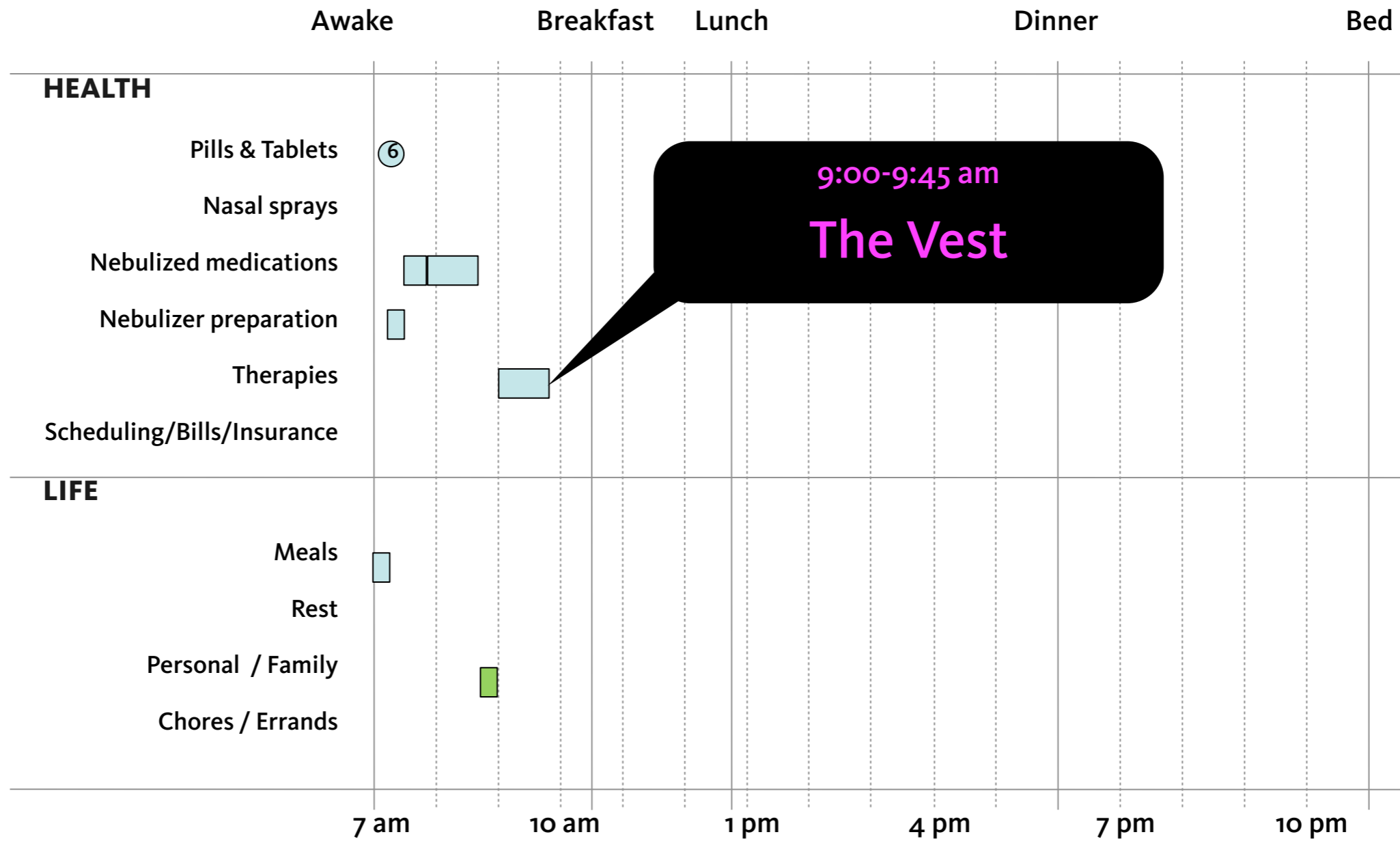


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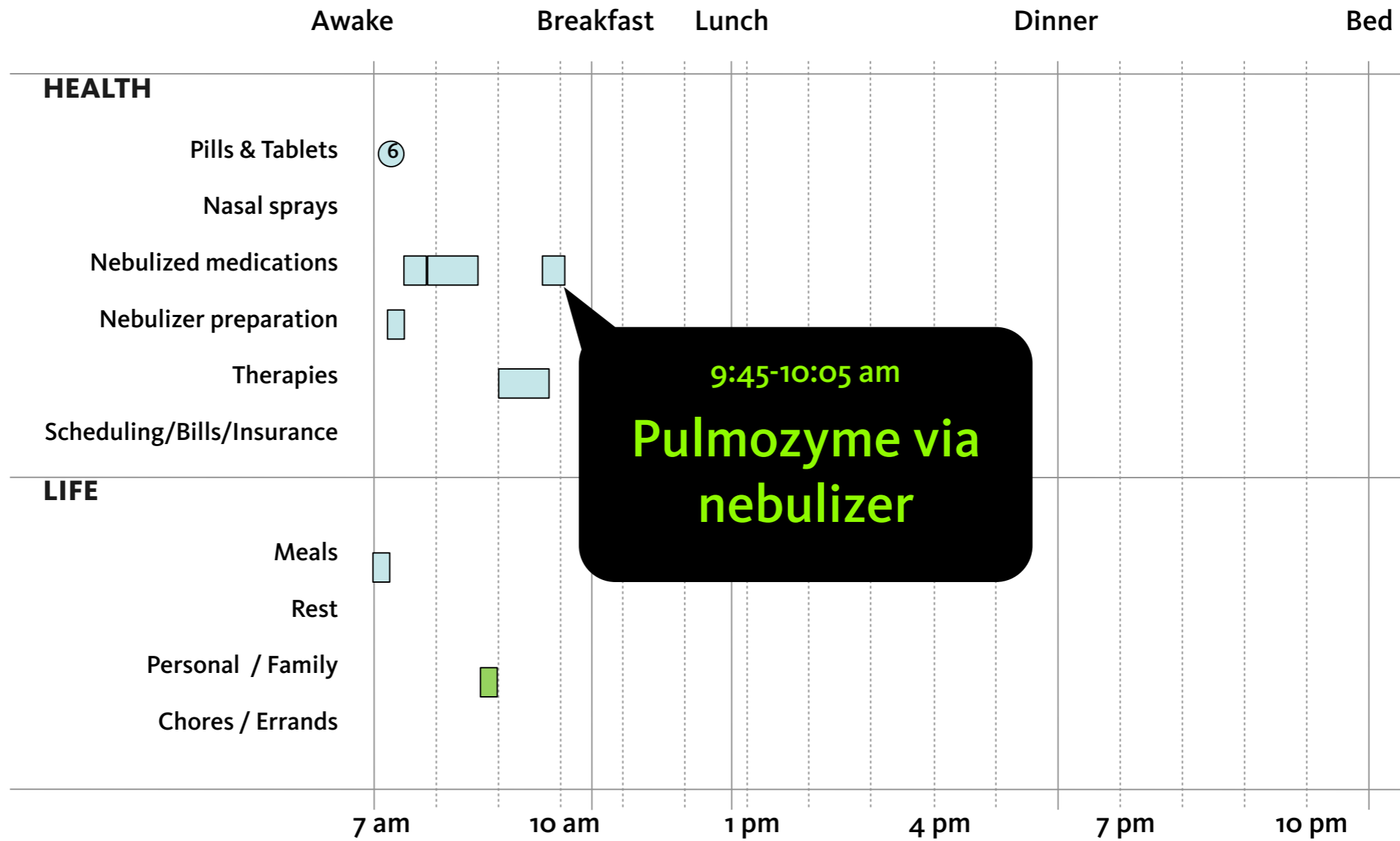


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- Other

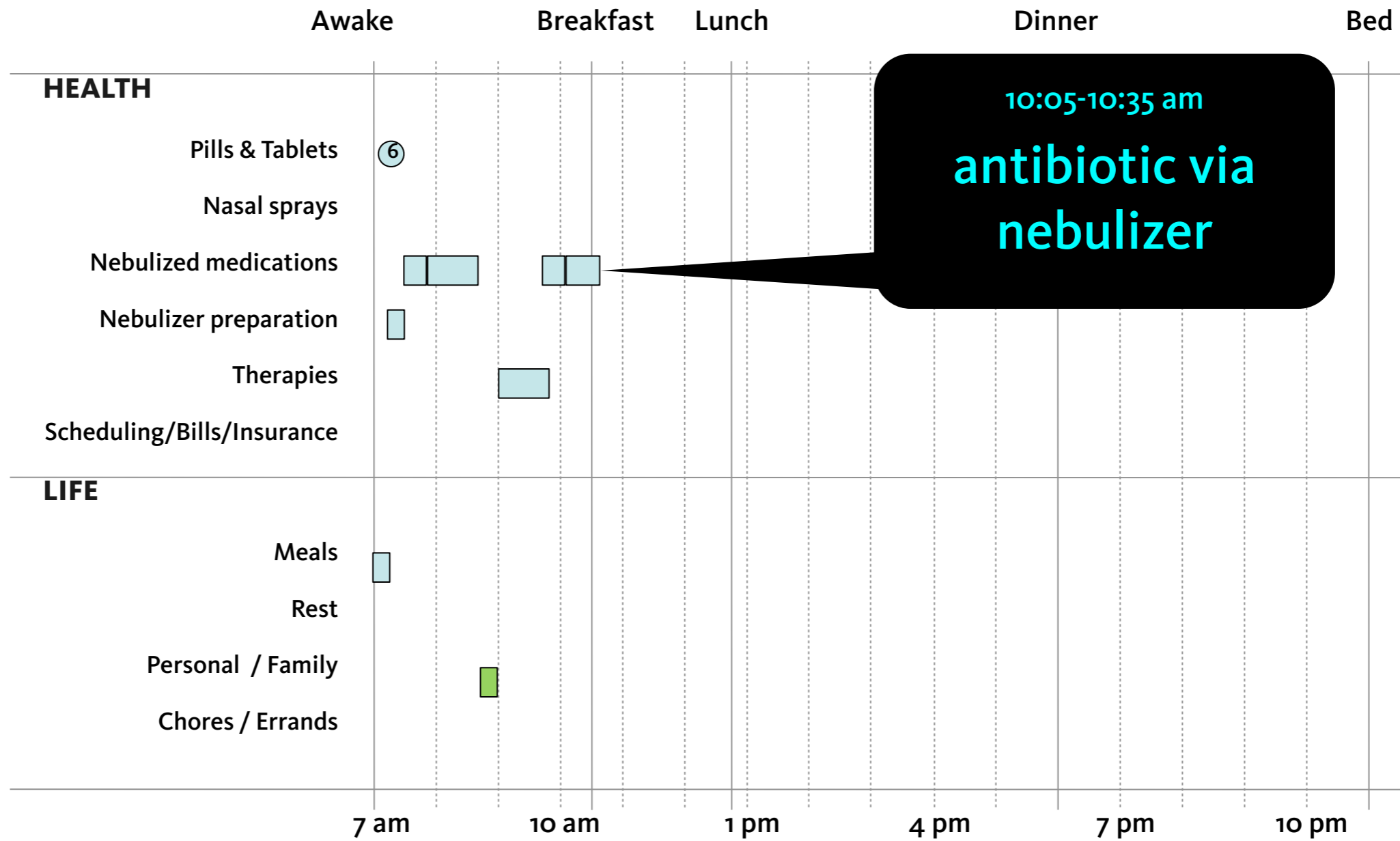


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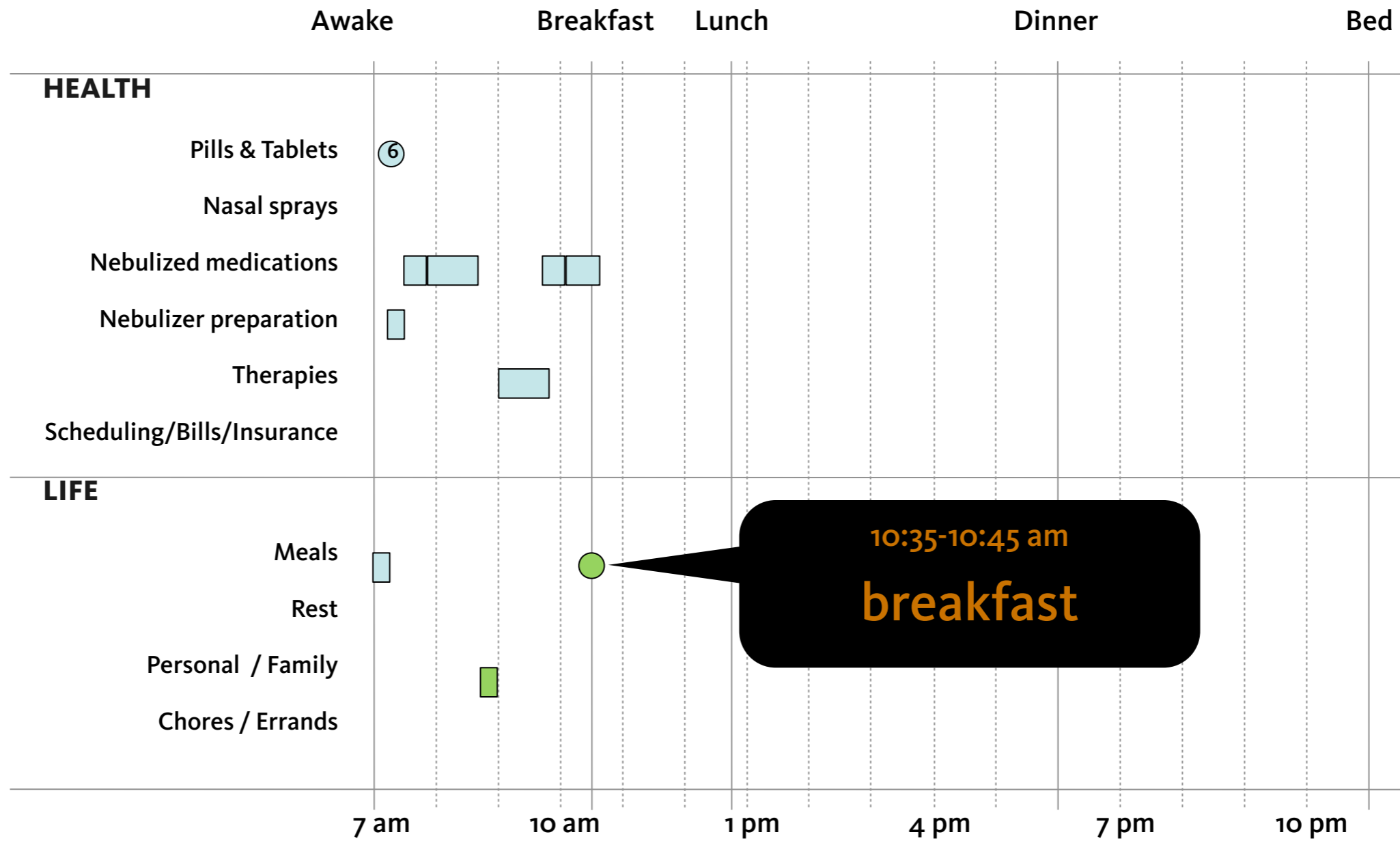


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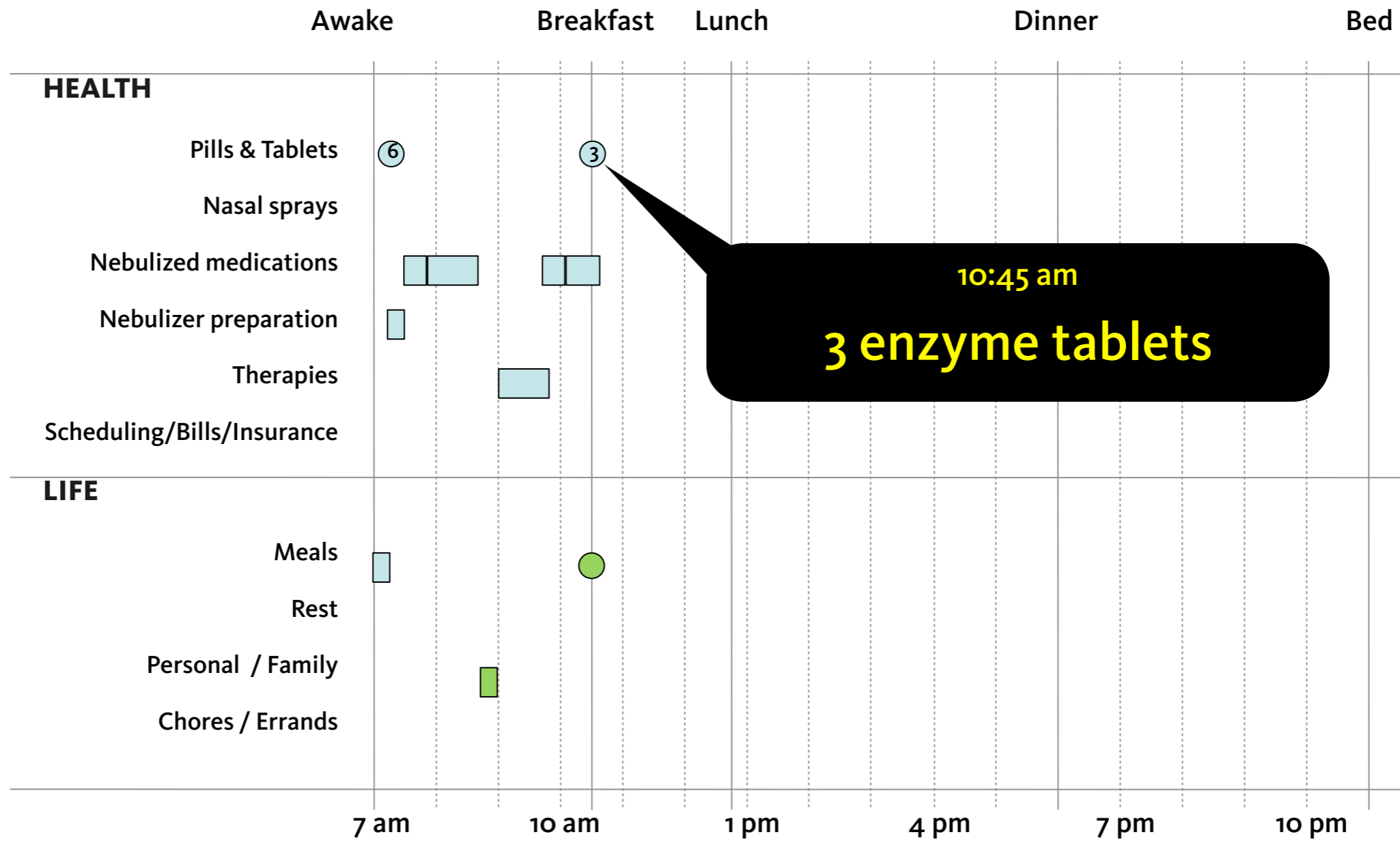
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Legend
● Health related
● Other

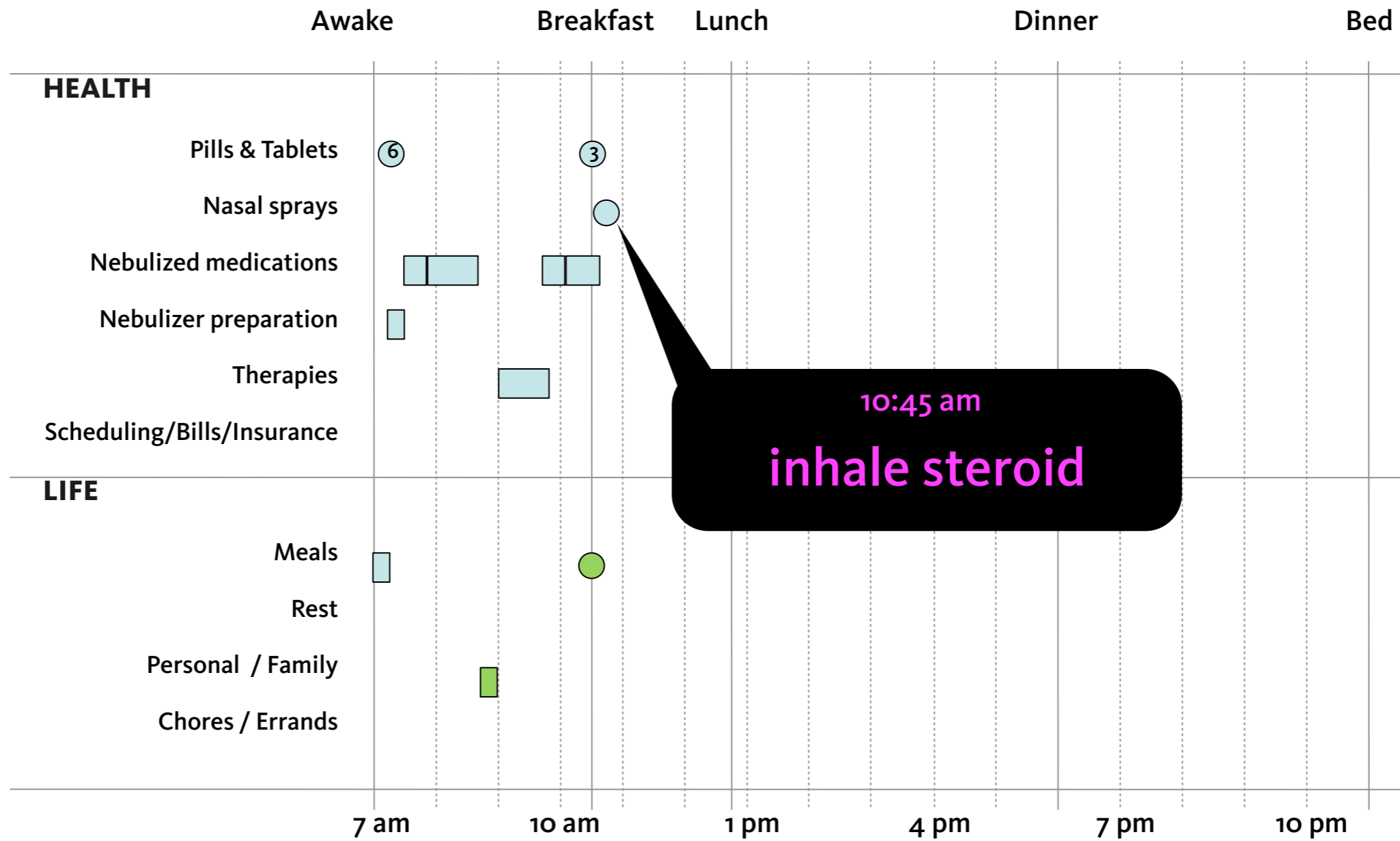


Cystic Fibrosis

woman; age 31; married; 2 yr old son

Legend

- Health related
- Other

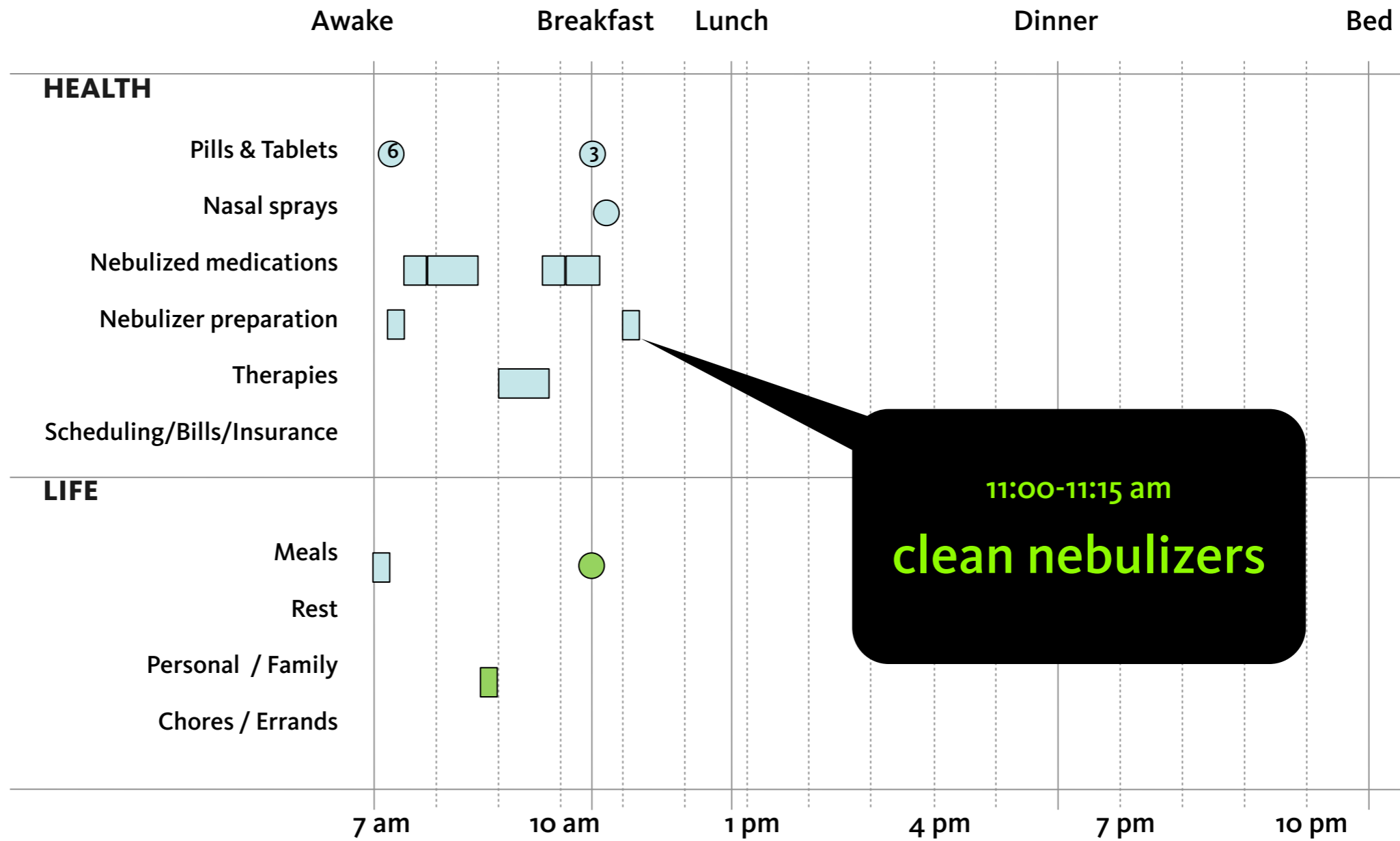


Cystic Fibrosis

woman; age 31; married; 2 yr old son

Legend

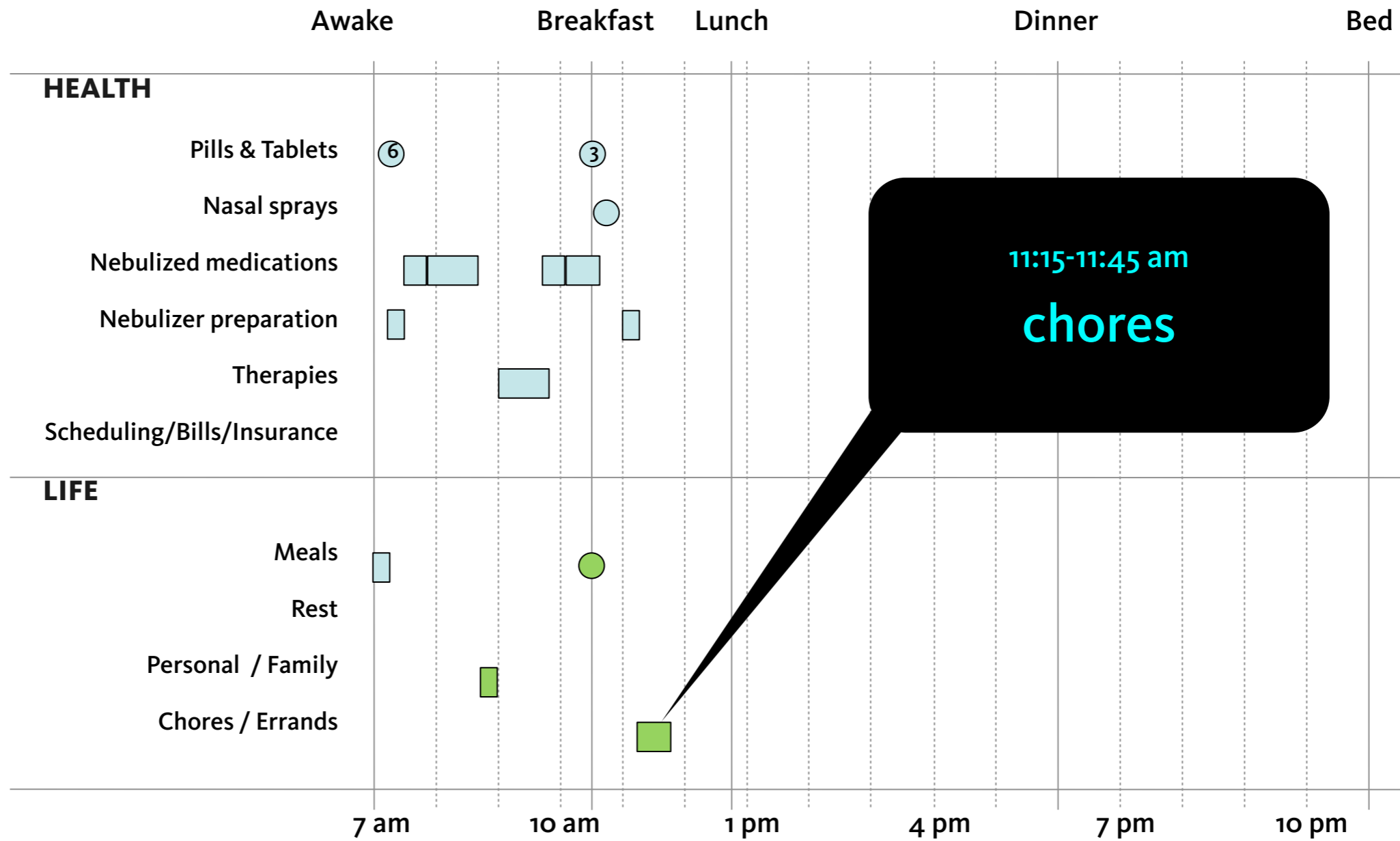
- Health related
- Other



Cystic Fibrosis

woman; age 31; married; 2 yr old son

Legend
● Health related
● Other

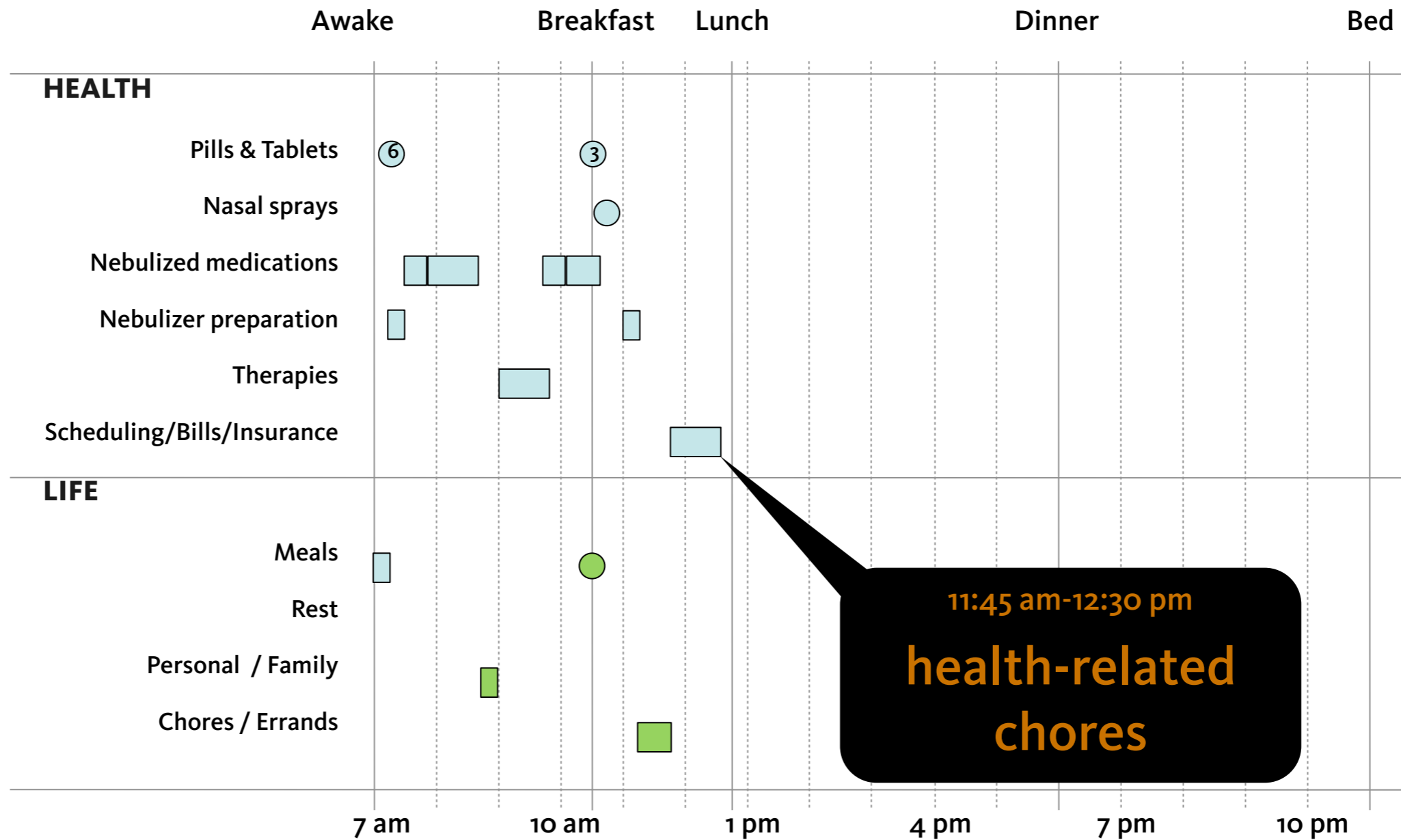


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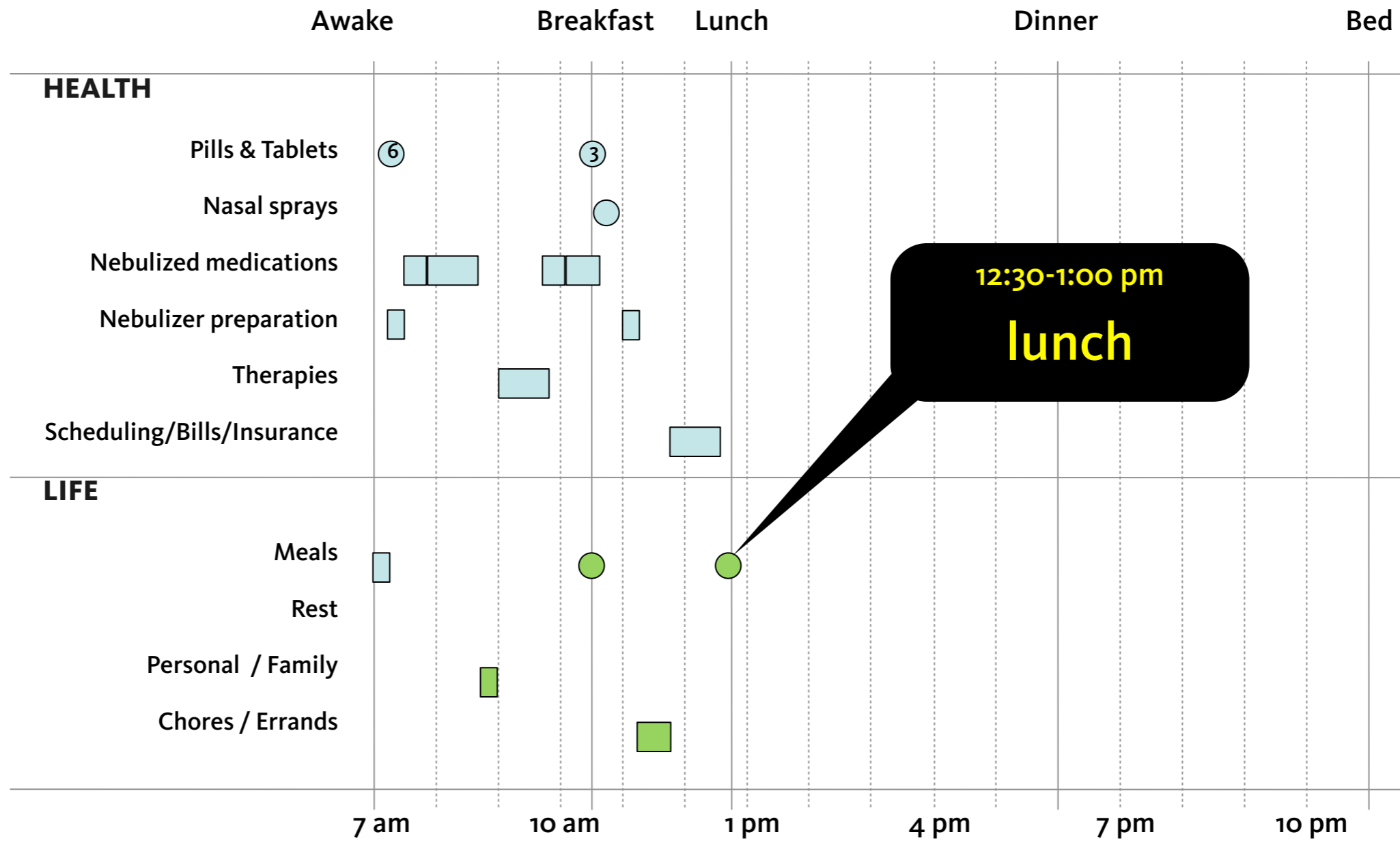
- Health related
- Other



Cystic Fibrosis

woman; age 31; married; 2 yr old son

Legend
● Health related
● Other

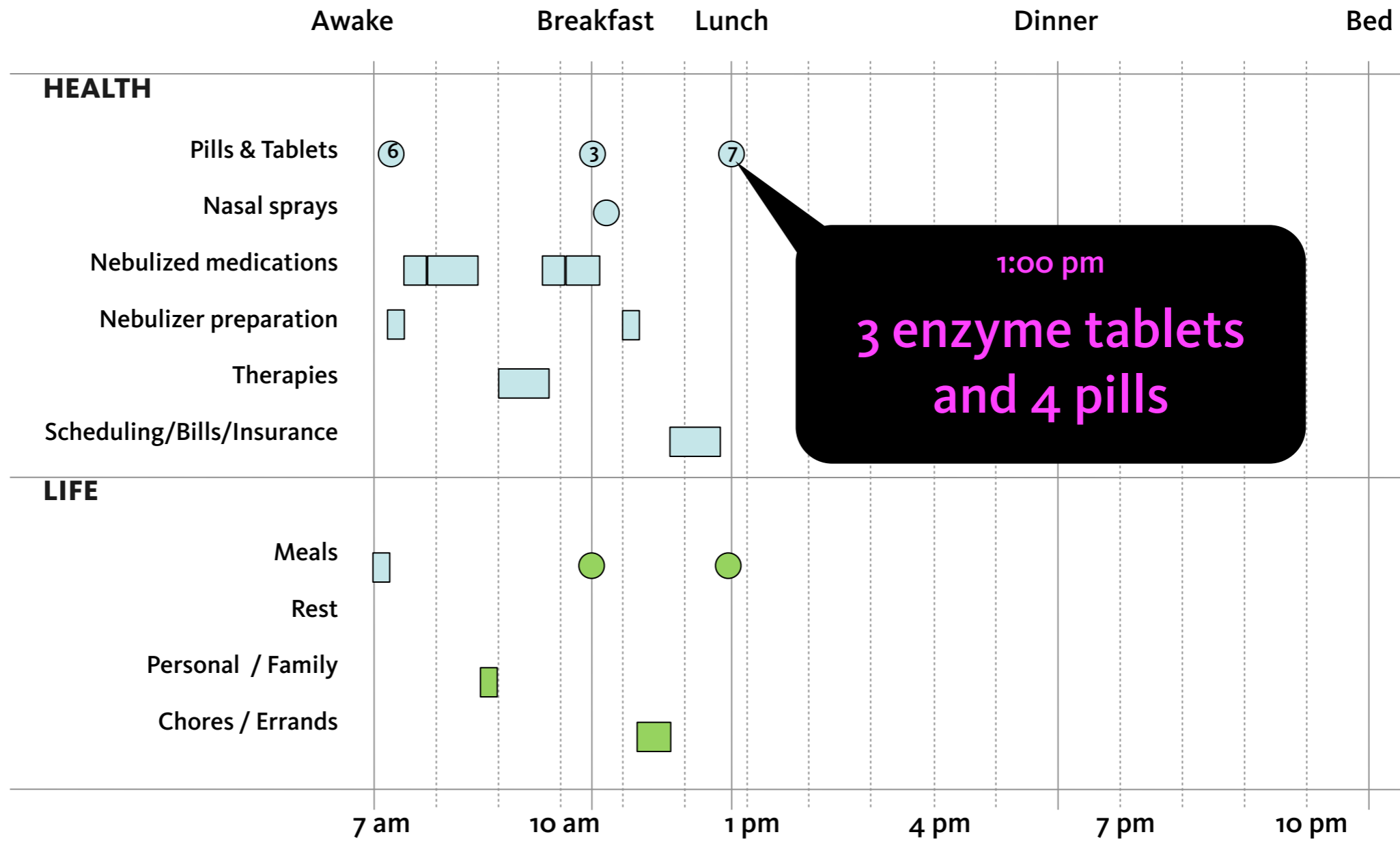


Cystic Fibrosis

woman; age 31; married; 2 yr old son

Legend

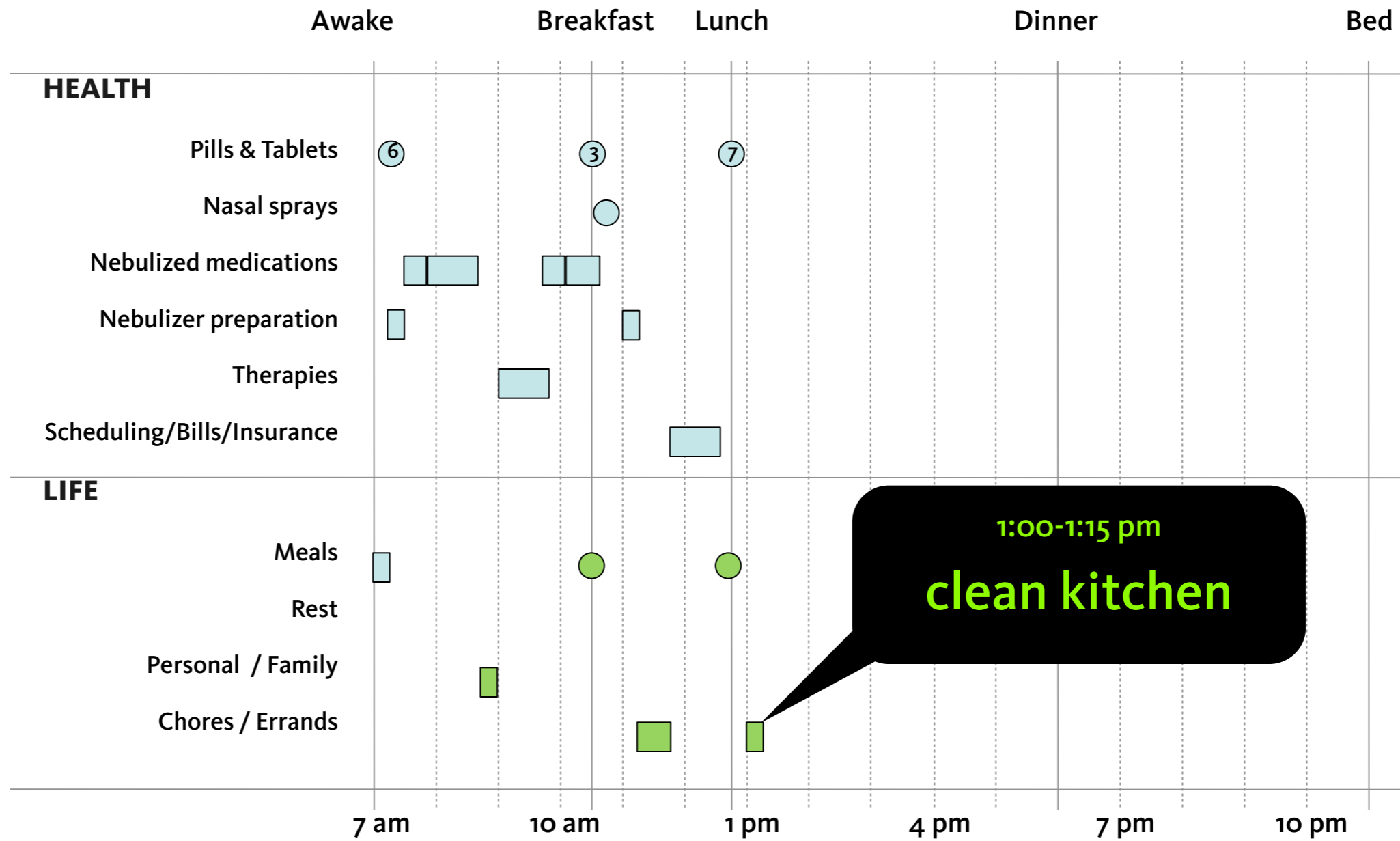
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- Other



Cystic Fibrosis

woman; age 31; married; 2 yr old son

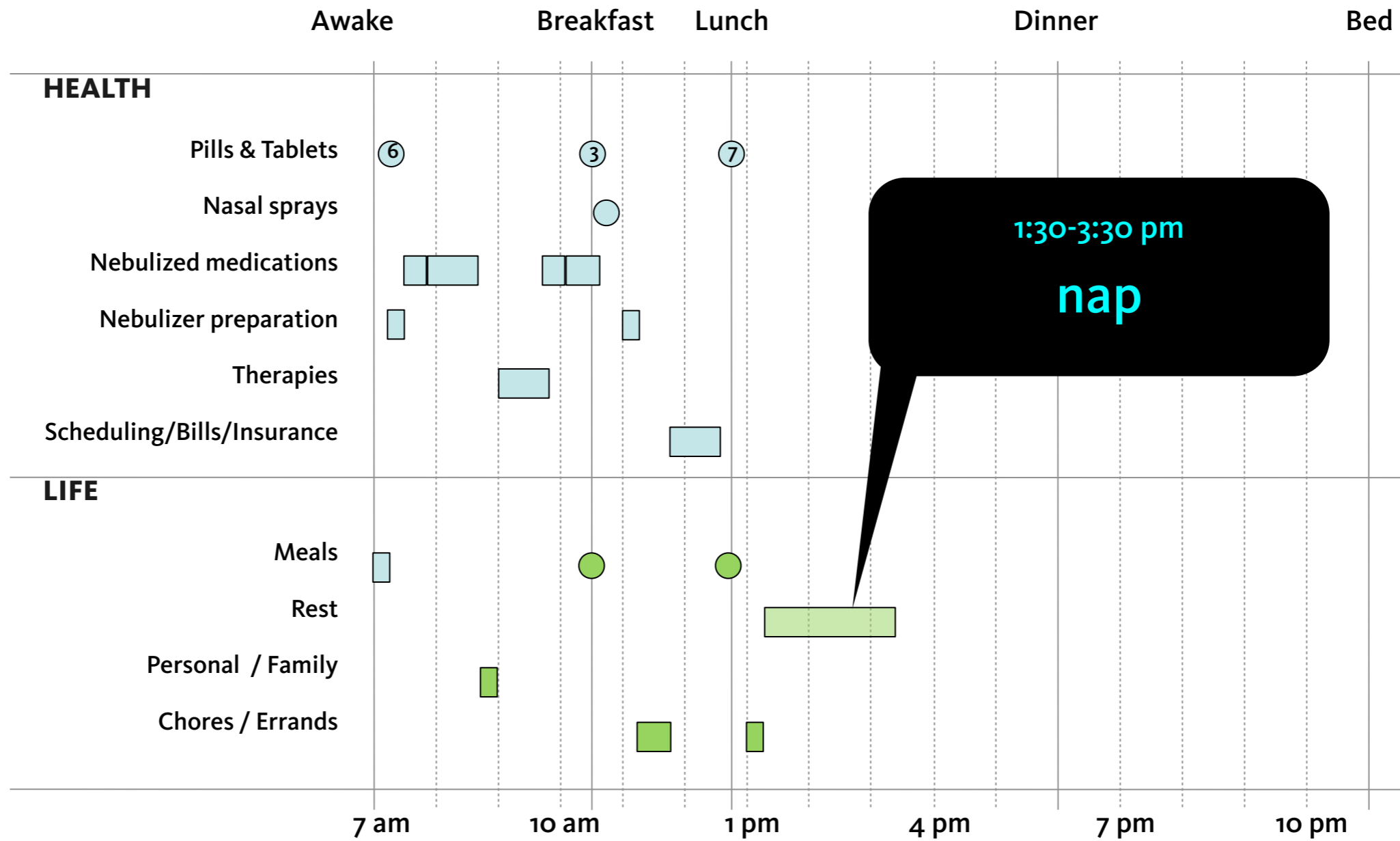
Legend
● Health related
● Other



Cystic Fibrosis

woman; age 31; married; 2 yr old son

Legend
● Health related
● Other

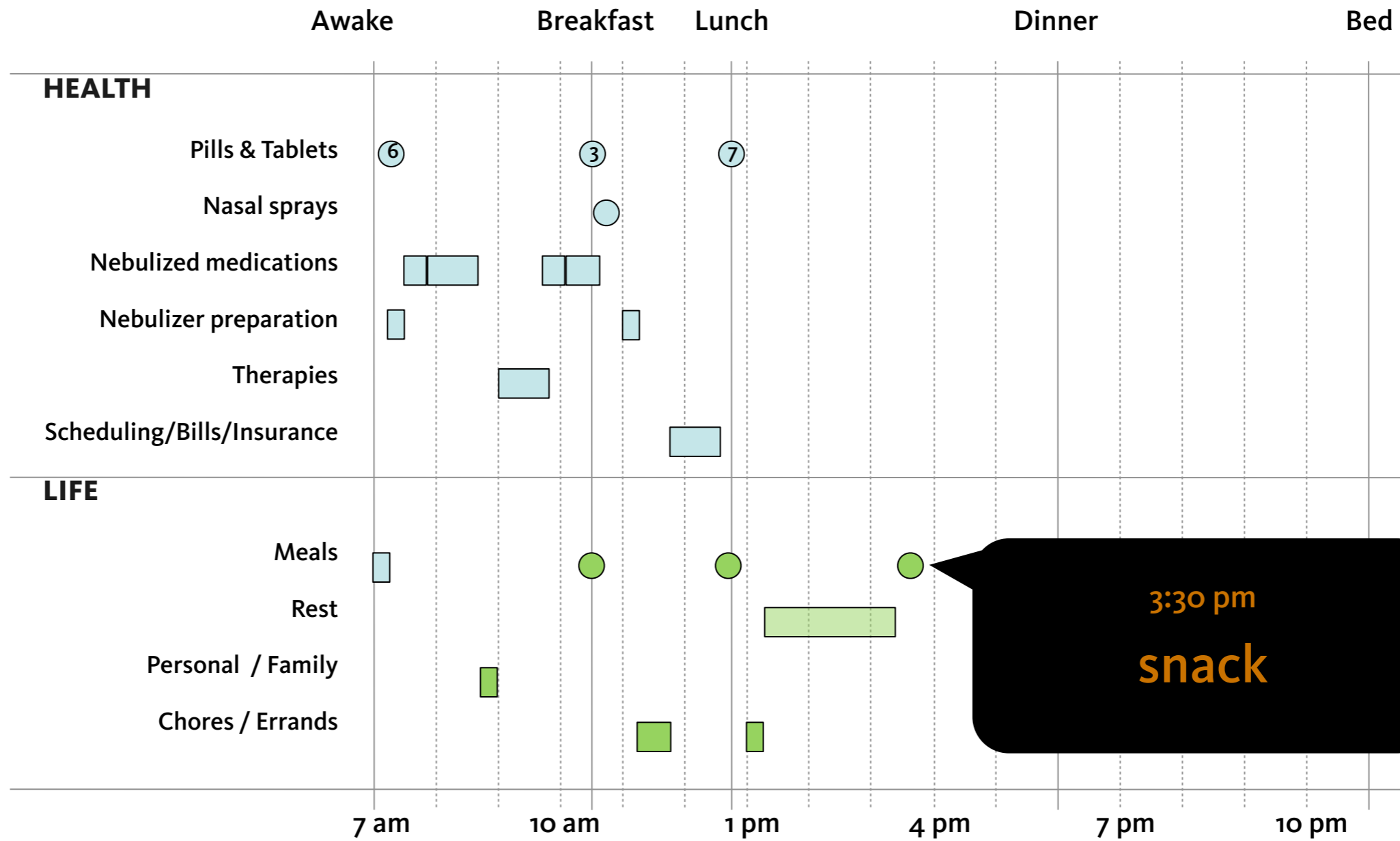


Cystic Fibrosis

woman; age 31; married; 2 yr old son

Legend

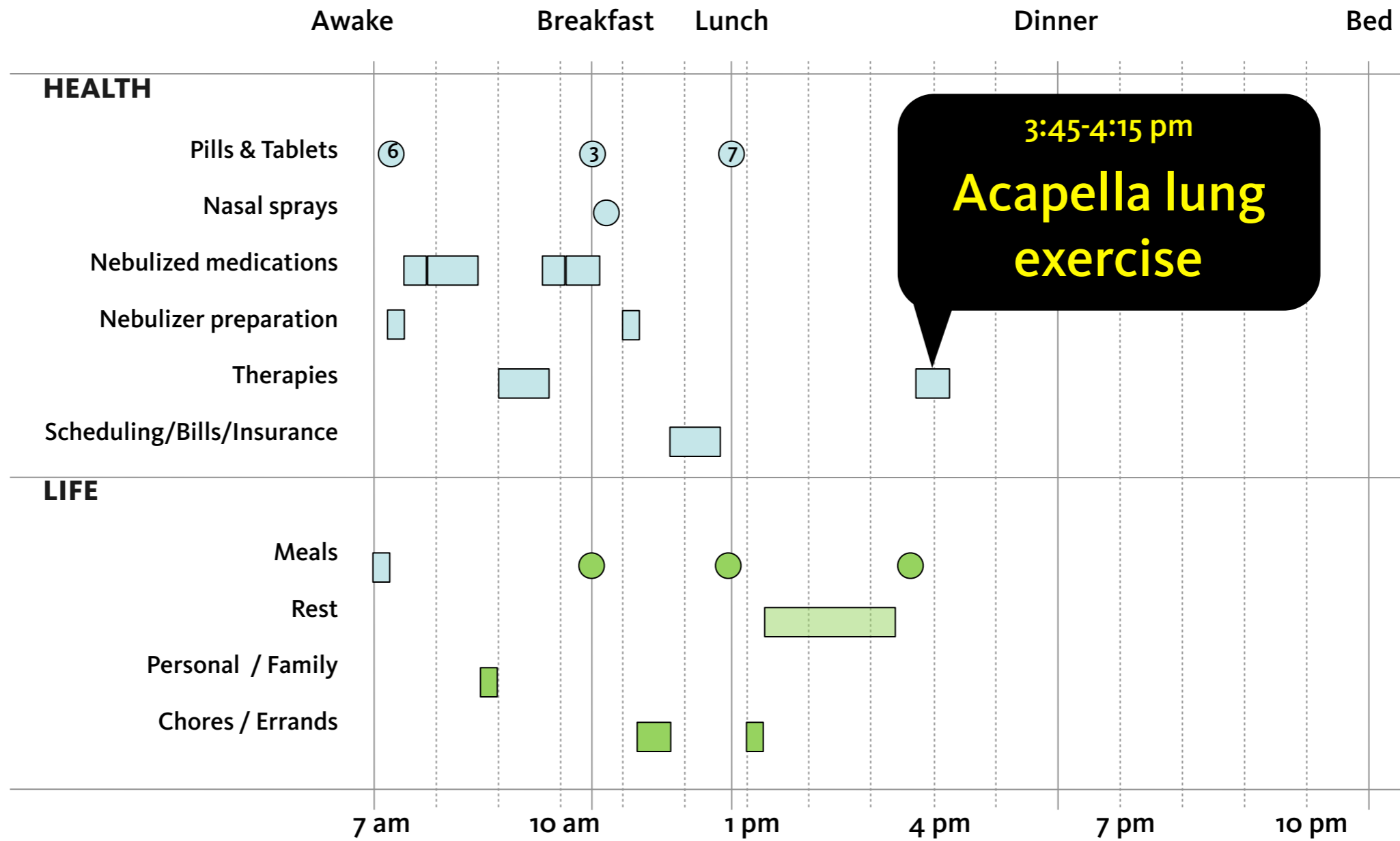
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Cystic Fibrosis

woman; age 31; married; 2 yr old son

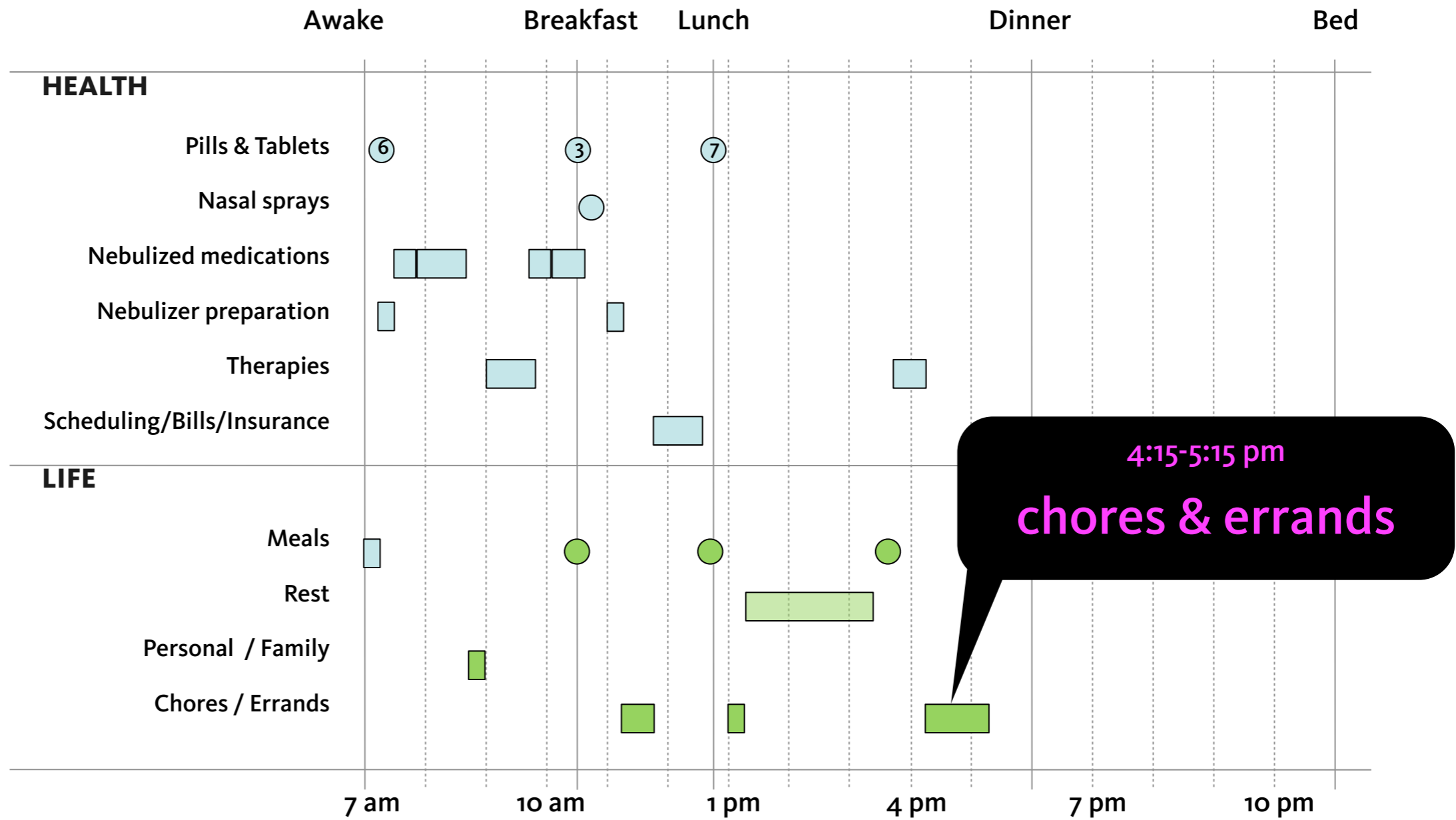
Legend
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● Other



Cystic Fibrosis

woman; age 31; married; 2 yr old son

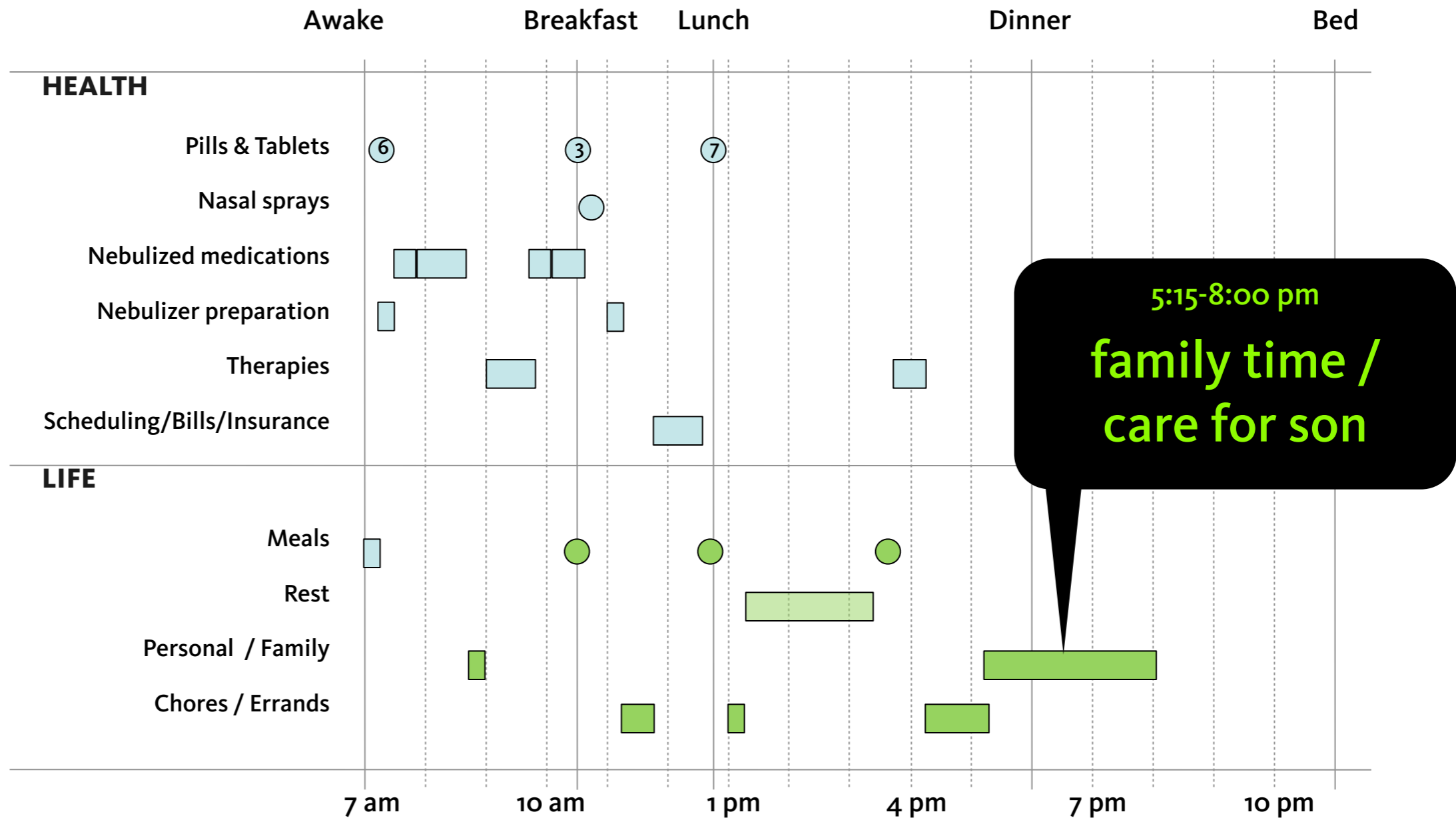
Legend
● Health related
● Other



Cystic Fibrosis

woman; age 31; married; 2 yr old son

Legend
● Health related
● Other

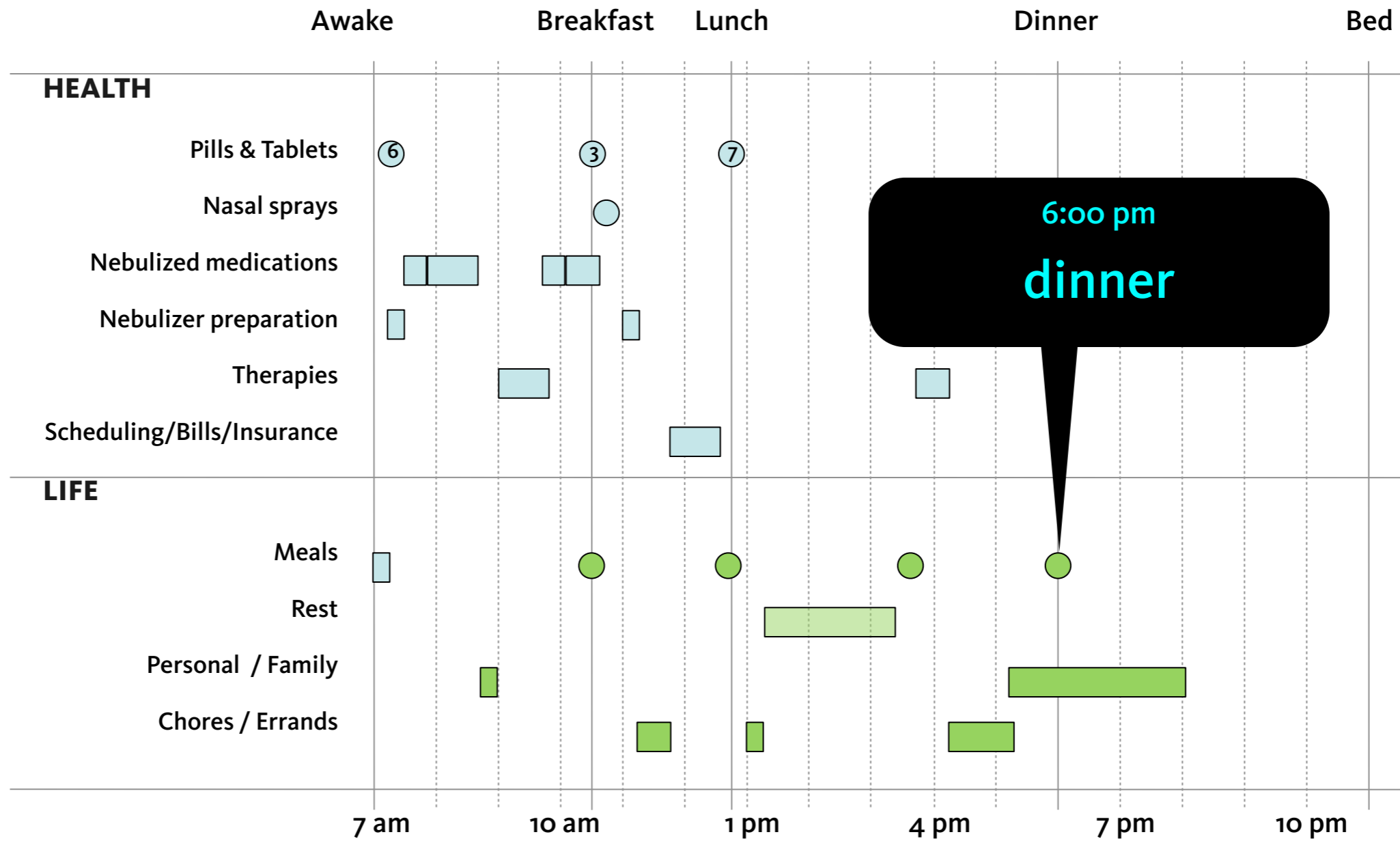


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woman; age 31; married; 2 yr old son

Legend

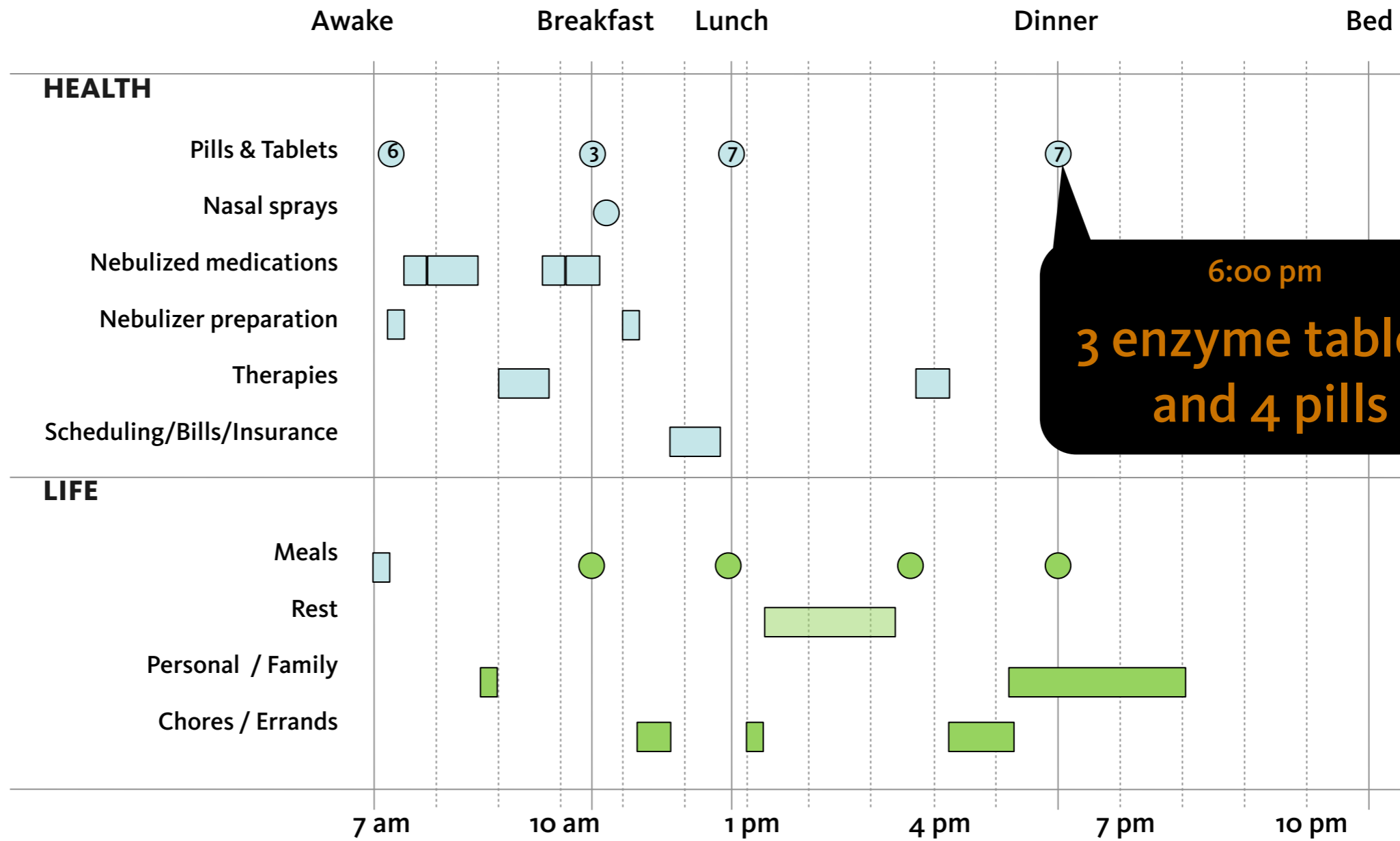
- Health related
- Other



Cystic Fibrosis

woman; age 31; married; 2 yr old son

Legend
● Health related
● Other

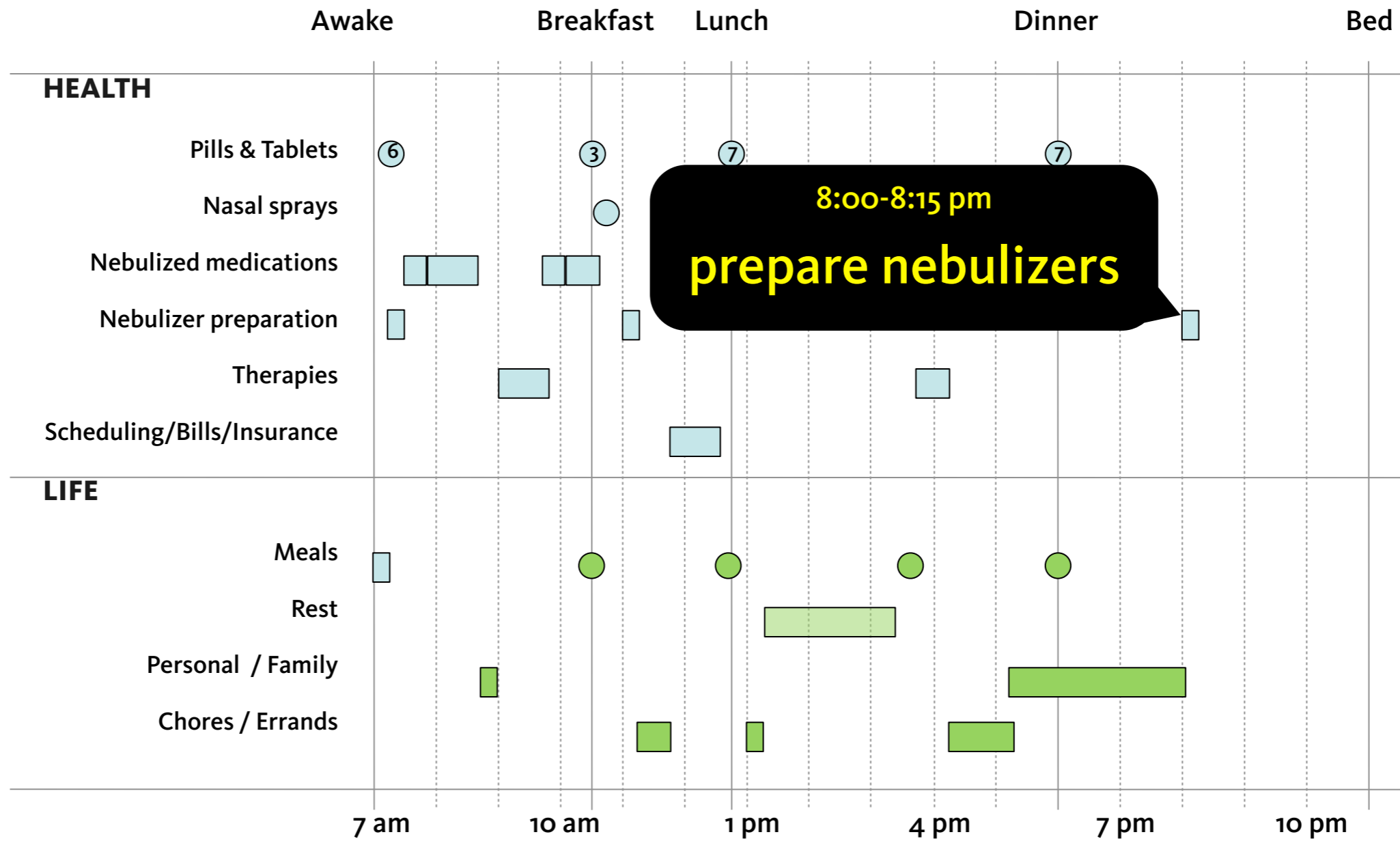


6:00 pm
3 enzyme tablets
and 4 pills

Cystic Fibrosis

woman; age 31; married; 2 yr old son

Legend
● Health related
● Other

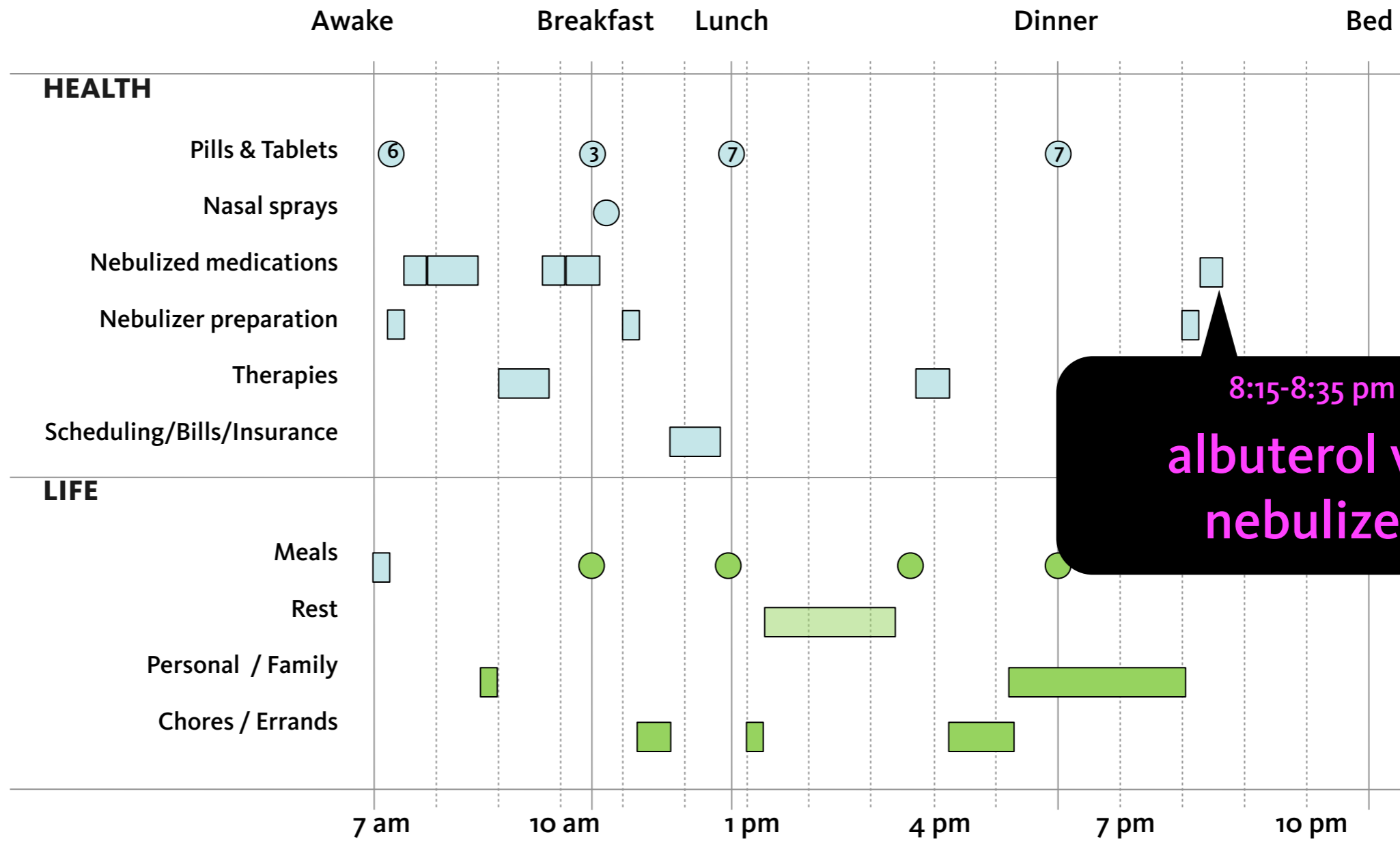


Cystic Fibrosis

woman; age 31; married; 2 yr old son

Legend

- Health related
- Other

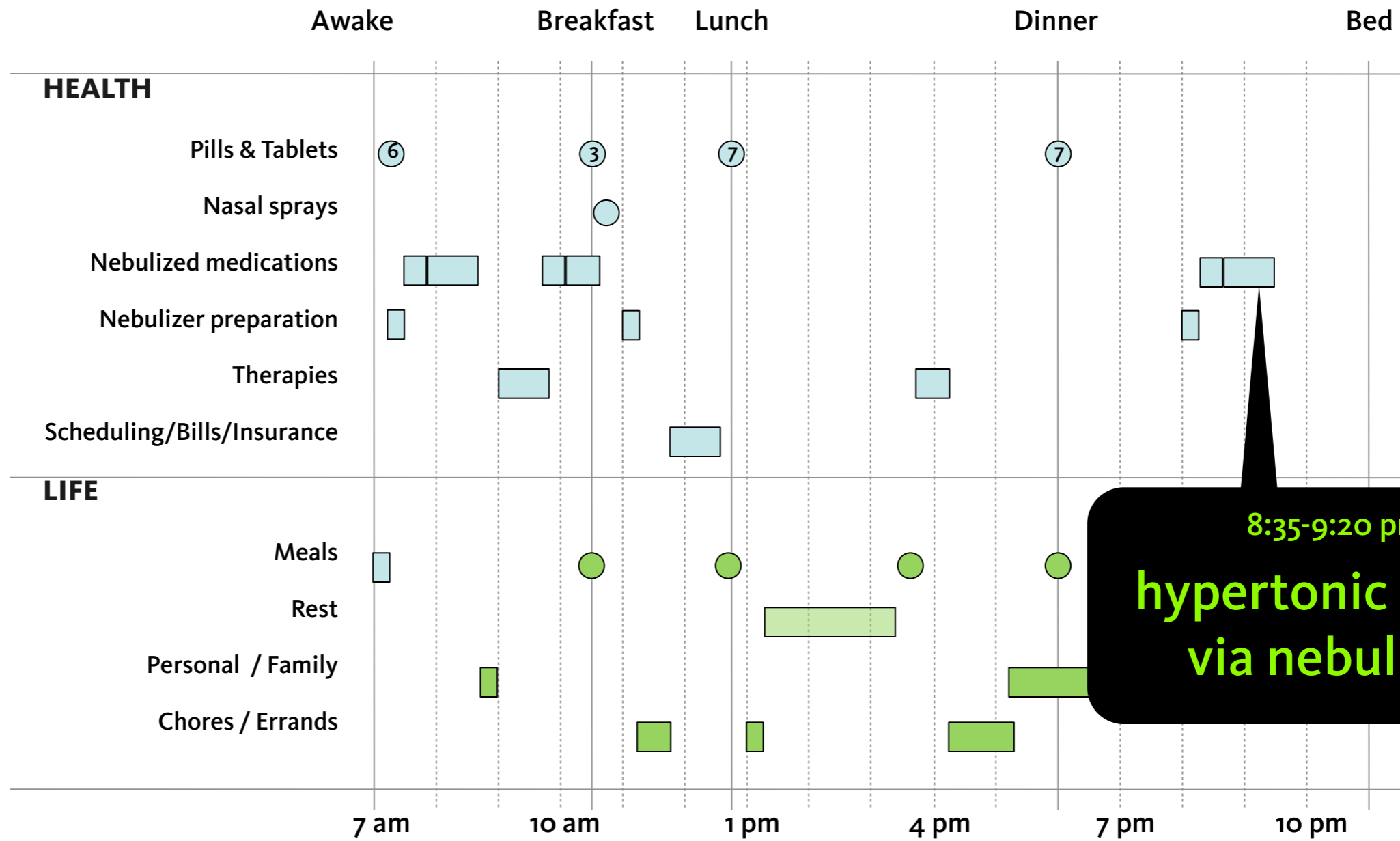


8:15-8:35 pm
albuterol via
nebulizer

Cystic Fibrosis

woman; age 31; married; 2 yr old son

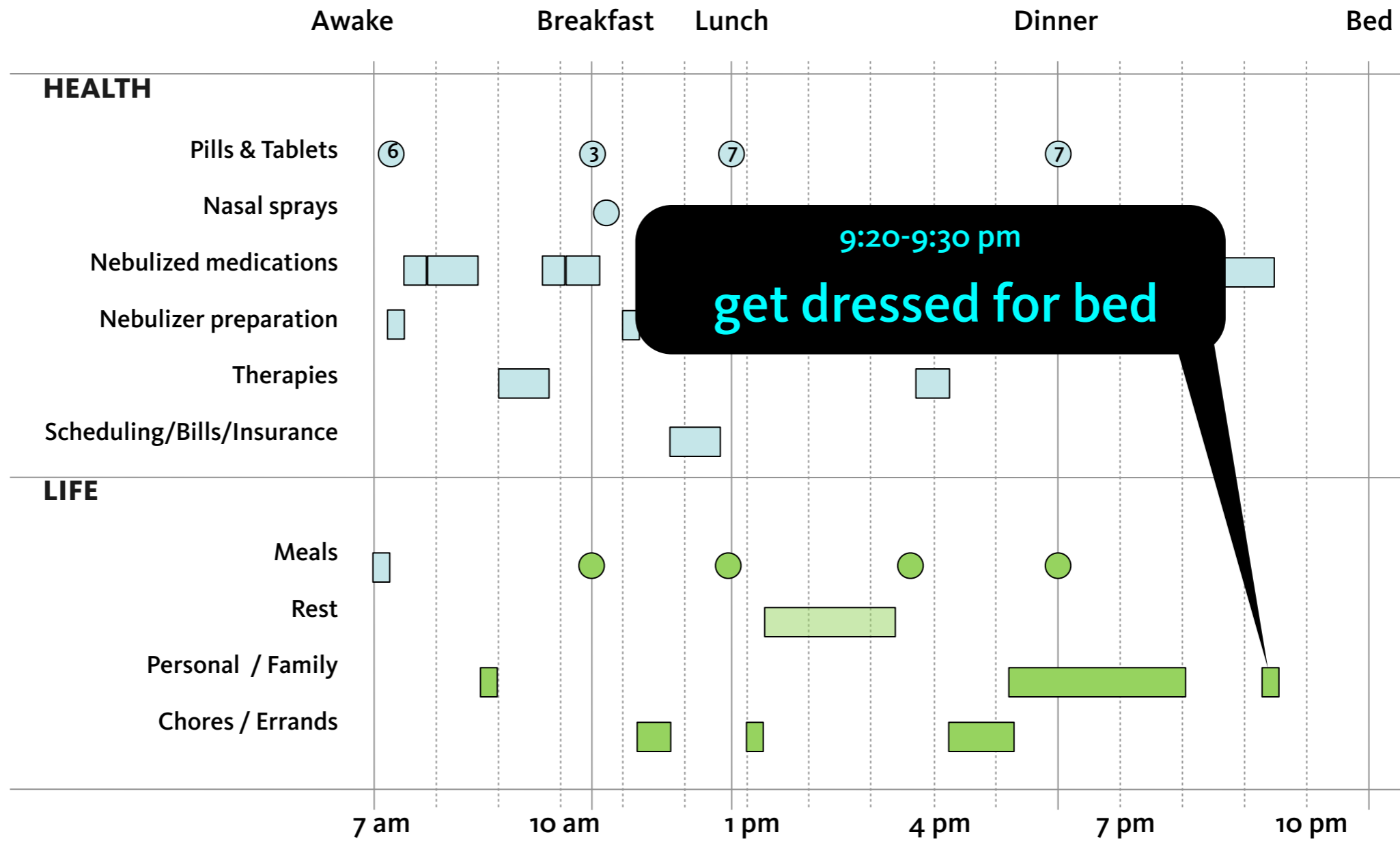
Legend
● Health related
● Other



Cystic Fibrosis

woman; age 31; married; 2 yr old son

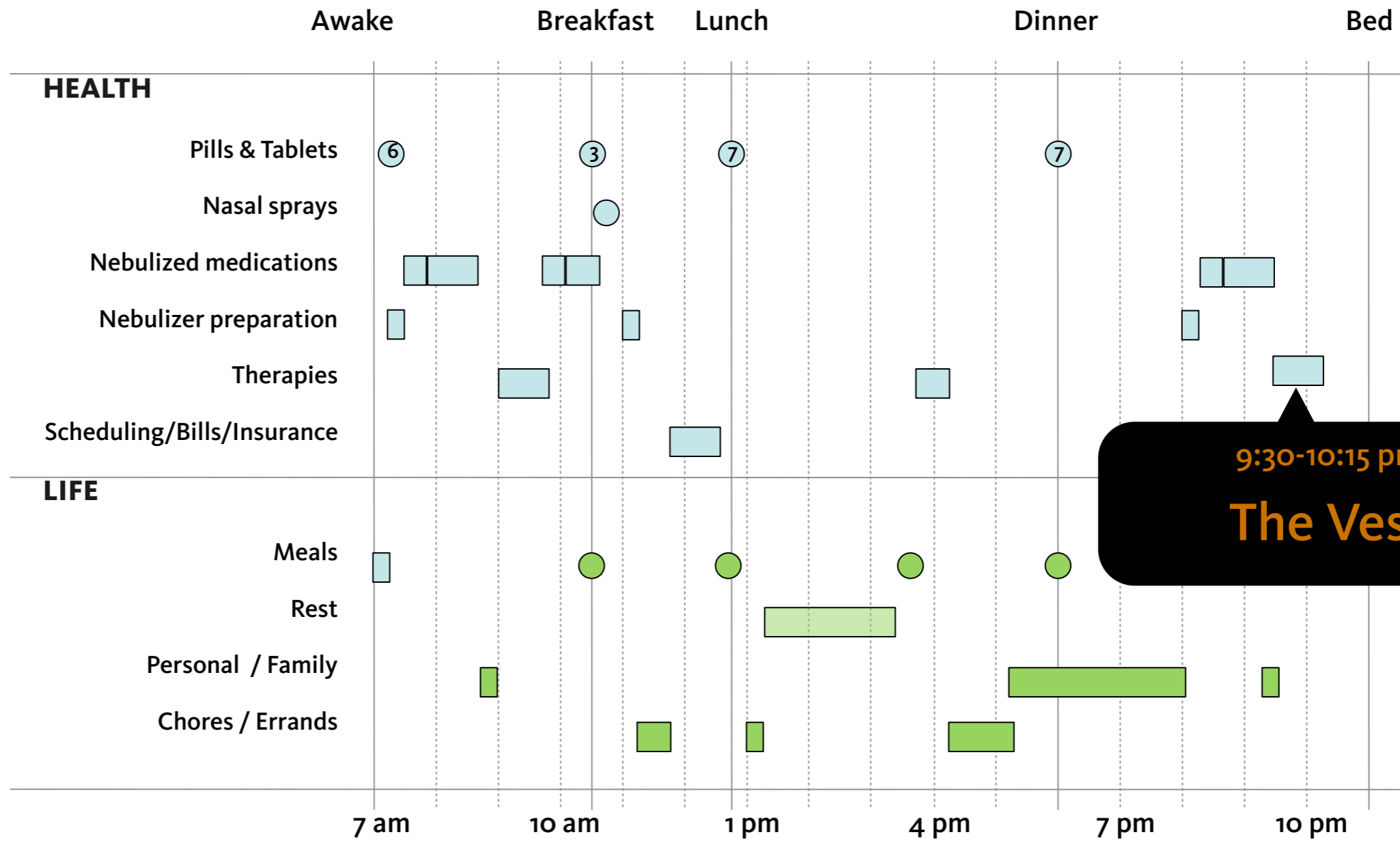
Legend
● Health related
● Other



Cystic Fibrosis

woman; age 31; married; 2 yr old son

Legend
● Health related
● Other

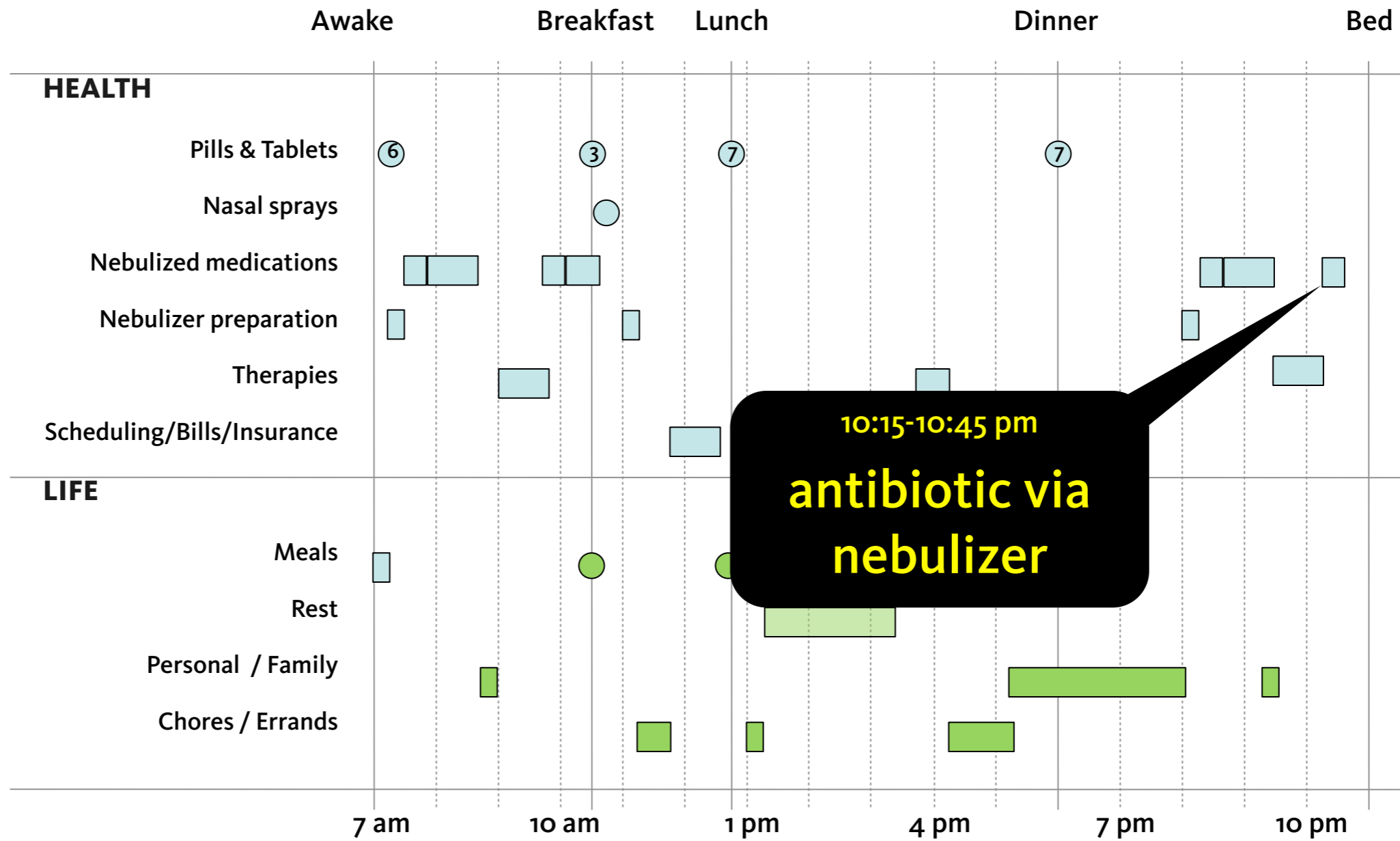


9:30-10:15 pm
The Vest

Cystic Fibrosis

woman; age 31; married; 2 yr old son

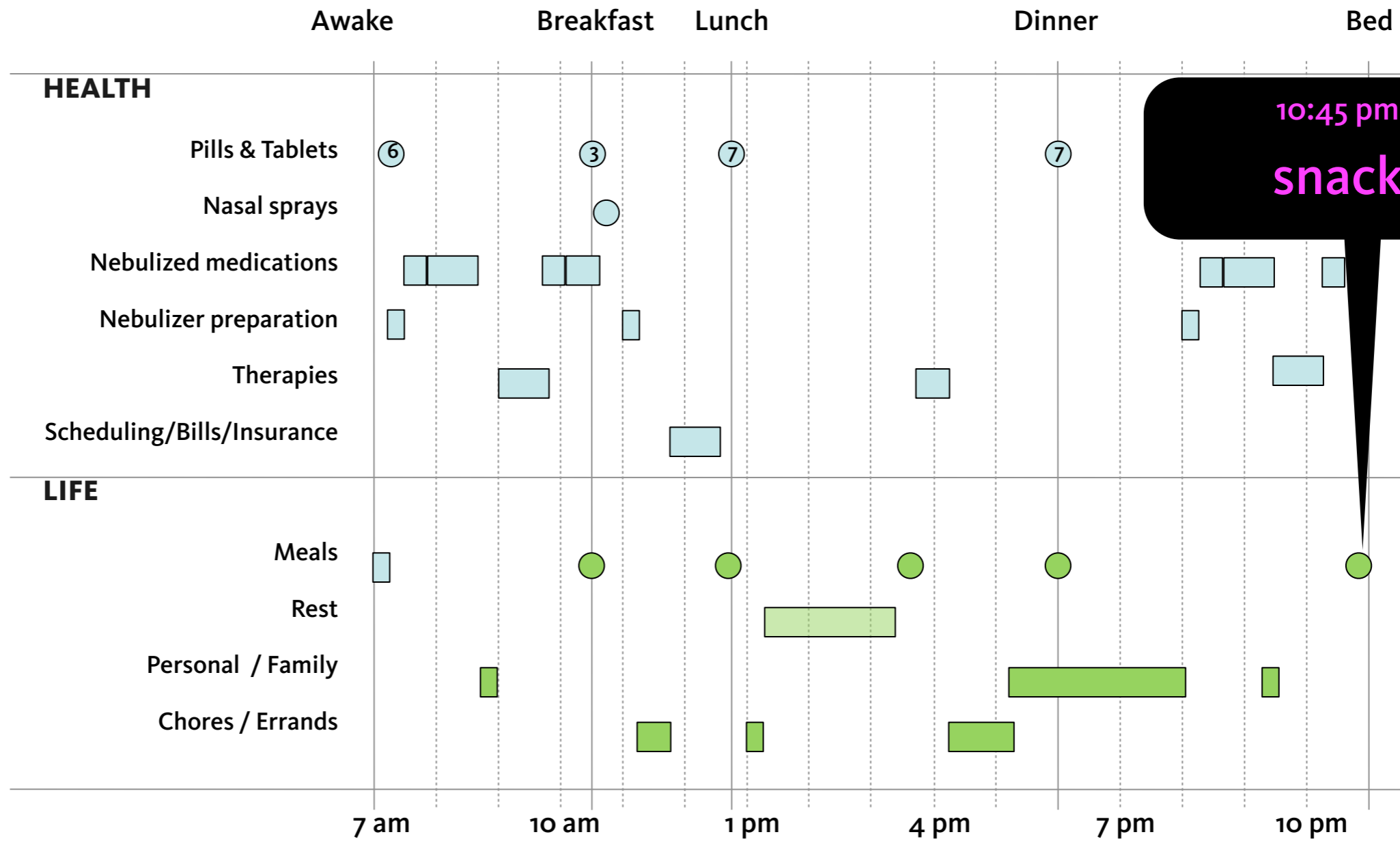
Legend
● Health related
● Other



Cystic Fibrosis

woman; age 31; married; 2 yr old son

Legend
● Health related
● Other

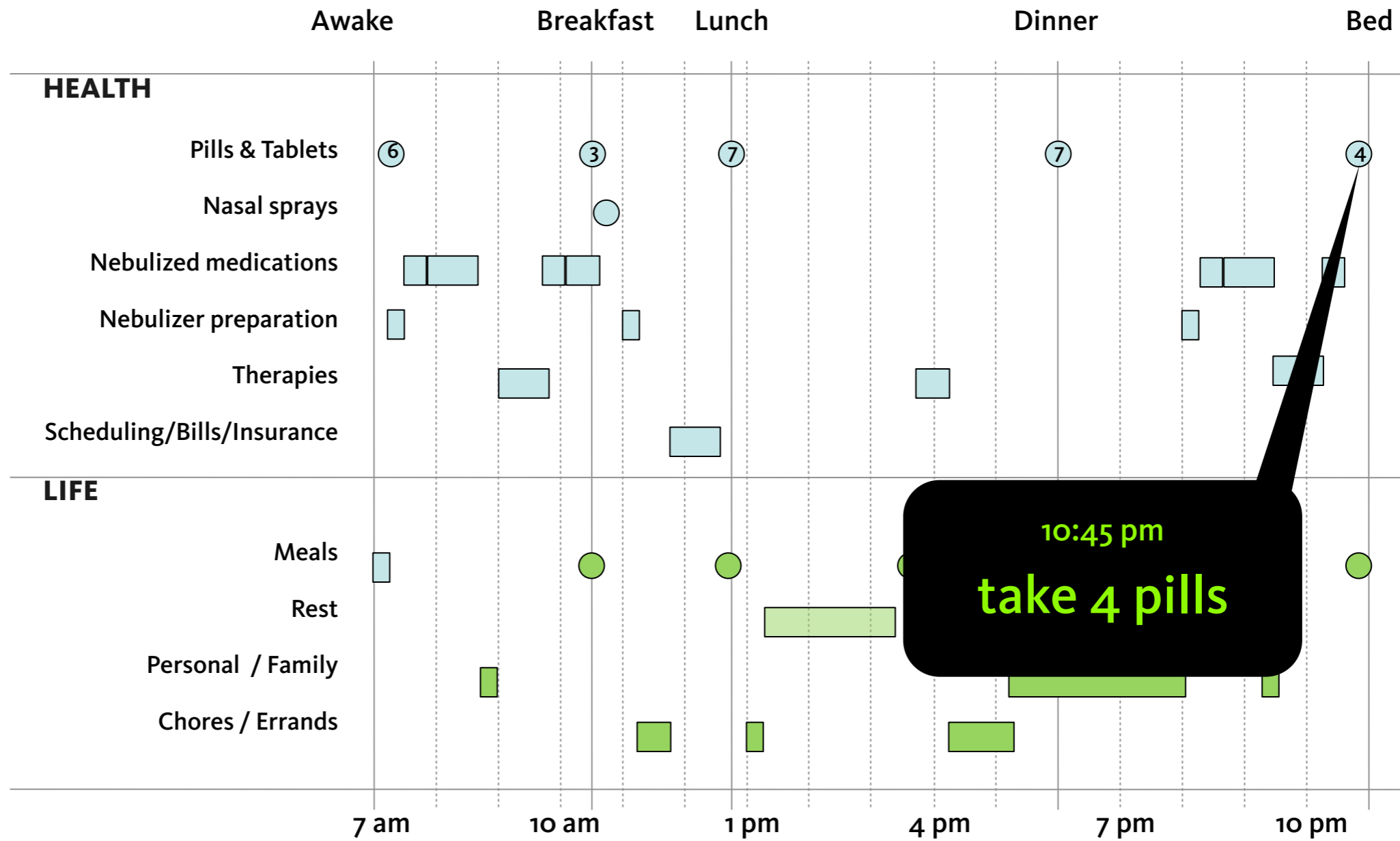


10:45 pm
snack

Cystic Fibrosis

woman; age 31; married; 2 yr old son

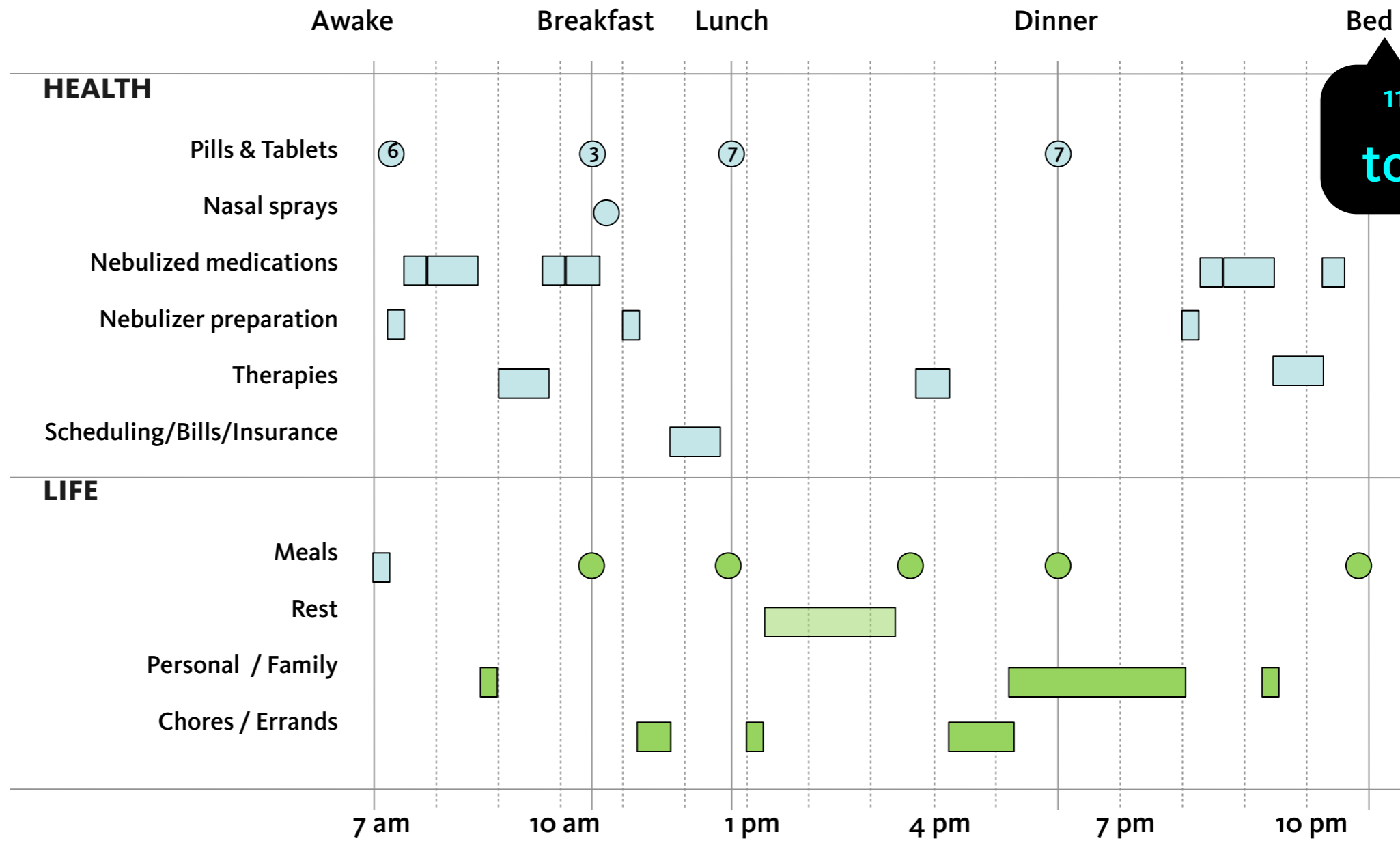
- Legend**
- Health related
 - Other



Cystic Fibrosis

woman; age 31; married; 2 yr old son

Legend
● Health related
● Other

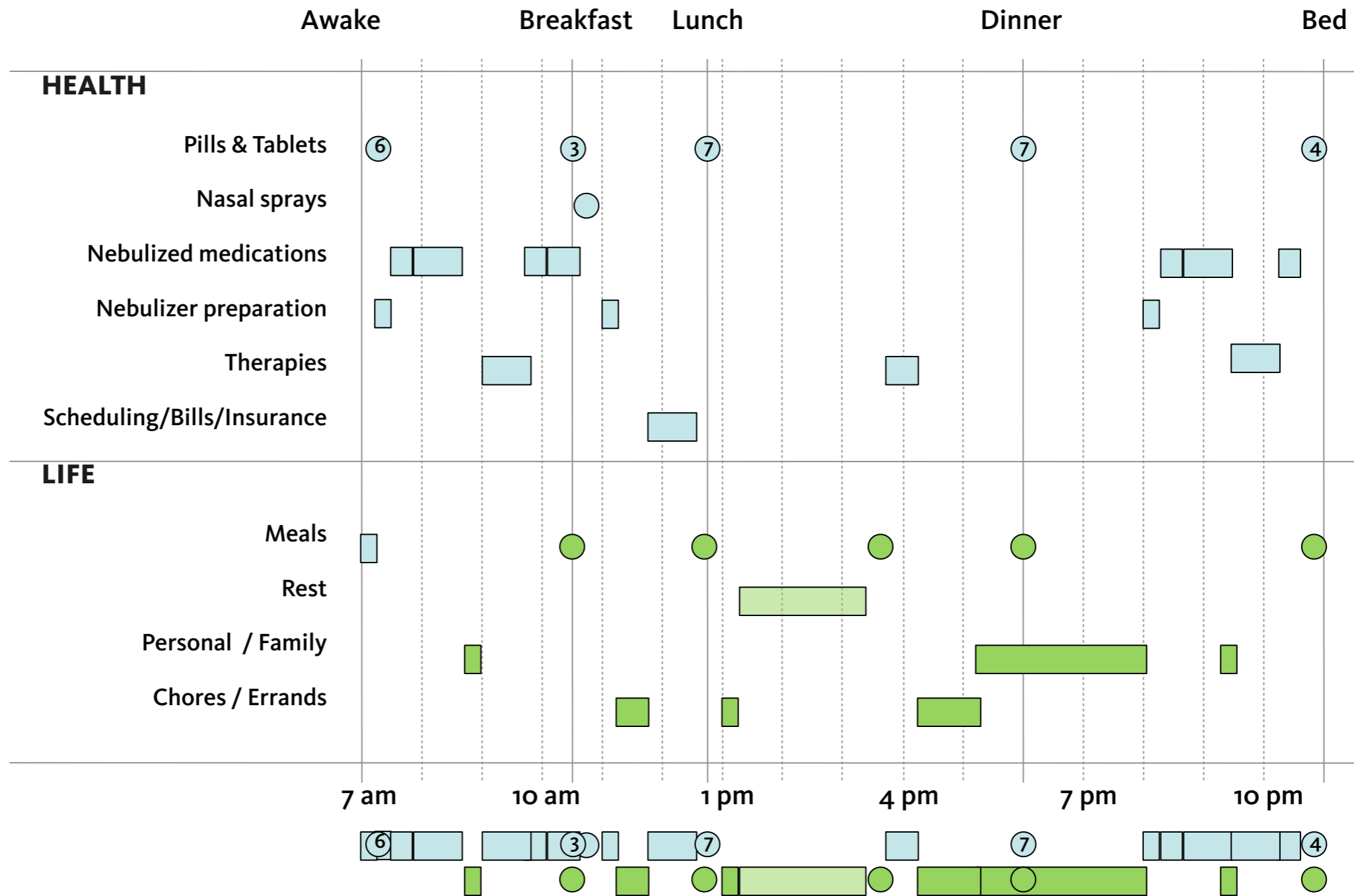


11:00 pm
to bed!

Cystic Fibrosis

woman; age 31; married; 2 yr old son

Legend
 ● Health related
 ● Other



Crohn's Disease

~500,000 adults

Medications

Humira
Azathioprine
Bupropion (depression)
Folic Acid
Vitamin B12
Calcium + Vitamin D

Therapies

Relaxation exercises

Biometrics

Weight
Temperature (as needed)

Exercise

Yoga
Walking

Diet

Meticulous food journaling

Health Status

Physical Symptoms

Fatigue
Nausea
Loss of appetite
Abdominal Pain
Diarrhea
Bloody Stools
Rectal Bleeding

Psychosocial Health

Mood
Anxiety
Stress
Overall Health

Medication Notes

SIDE EFFECTS
Injection site pain/red/swelling
Rash
Shortness of Breath
Joint pain
CONTRA-INDICATIONS
Cold or Sinus Infections

Context

Social

Activities
Social interaction

Work

Workload
Work conditions

Geographic

Location
Environmental stressors

Diabetes

~24m adults have diabetes (mainly type 2)

~10m have 1 additional chronic illness

~ 6m have 2 or more additional chronic illnesses

Medications

Insulin Novolin
Insulin Novolog
Metformin
ACE inhibitor
Multi-vitamin
Ibuprofen

Therapies

Foot massage

Biometrics

Blood glucose
Blood pressure / pulse
Weight

Exercise

Various

Diet

Food journal
Calorie counting

Health Status

Physical Symptoms

Fatigue
Frequent urination
Excessive thirst
Sudden weight loss
Blurred vision
Cold sweat
Headache

Psychosocial Health

Mood
Anxiety
Stress
Overall Health

Medication Notes

Side effects, such as...
Injection site pain/redness/swelling
Rash
Shortness of breath

Context

Social

Activities
Social interaction

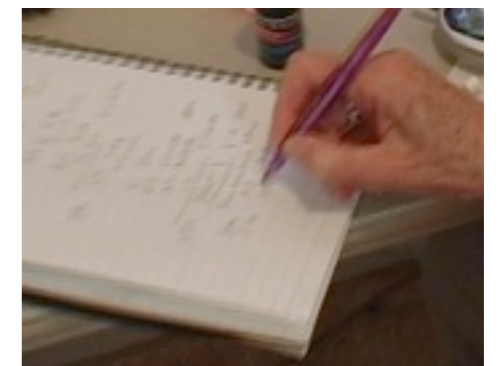
Work

Workload
Work conditions

Geographic

Location
Environmental stressors

... and cope with Health



What is health?

Traditional frame: illness

Today, health is often seen as the absence of disease or infirmity.

Traditional health-care focuses on acute problems

Goals Eliminate or minimize
acute disease and infirmities



Means Medicine and therapies
administered by HCPs
with patient's consent;
patients have little say in
means

Health-management focuses on chronic conditions

Goals Eliminate or minimize acute disease and infirmities



Means Medicine and therapies administered by HCPs with patient's consent; patients have little say in means

Manage chronic conditions; avoid or slow deterioration leading to acute problems



Medicine and therapies prescribed by physicians and administered by patients, who may have other priorities or may reject means

Reframing: Well-being

Health is a state
of complete physical, mental,
and social well-being
and not merely the absence
of disease or infirmity.

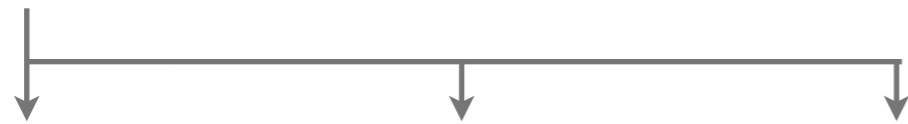
—World Health Organization (WHO), 1948

Health is “a resource for life,
not the objective of living”

—World Health Organization (WHO), 1986

Well-being depends on more than health-care

Goals Health: complete physical, mental and social well-being



Means Acute care

Chronic care

Self-management supported by HCPs, friends, and family

Other means, such as:

- Employer practices
- Social policies
- Essentials:
 - clean air + water
 - food + shelter
 - education + stability

Well-being is a means, not an end

Goals Quality of everyday living



Means Health: complete physical, mental and social well-being

Other goals/means, such as:

Means Acute care

Chronic care

Self-management supported by HCPs, friends, and family

- Love of family + friends
- Valued work
- Financial security
- Physical security
- Participation in society
- Fun + joy

Other means, such as:

- Employer practices
- Social policies
- Essentials:
 - clean air + water
 - food + shelter
 - education + stability

What is self-management?

Goals Quality of everyday living



Means Health: complete physical, mental and social well-being



Means Acute care

Means Chronic care

Means Self-management supported by HCPs, friends, and family



Means Medicines + therapies

Means Medicines + therapies

Means People actively involved in their own:

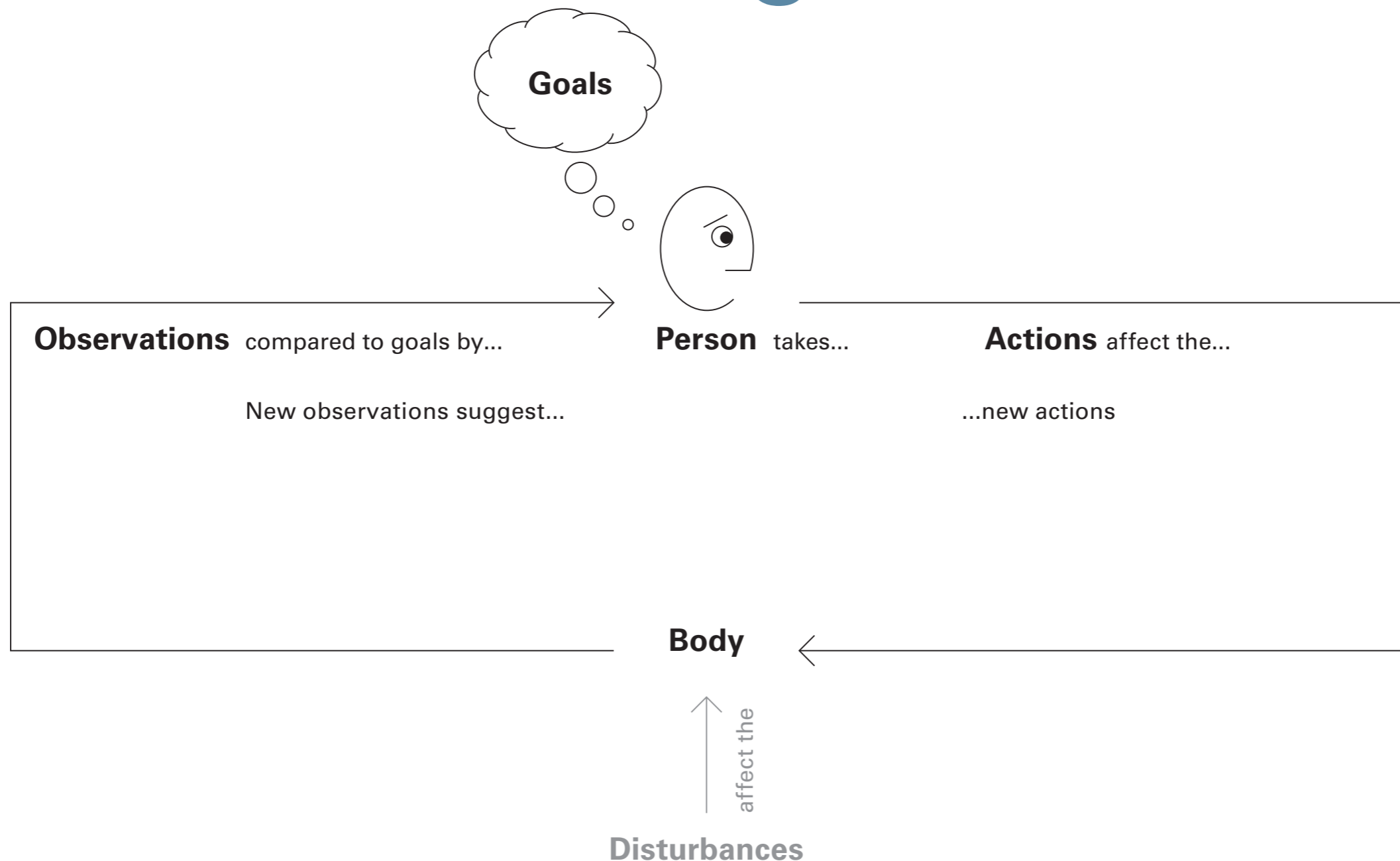
- monitoring...
- goal-setting...
- experimenting...
- understanding...
- reflecting...

...in relation to their:

- bodies
- diet
- activities
- relationships
- environment

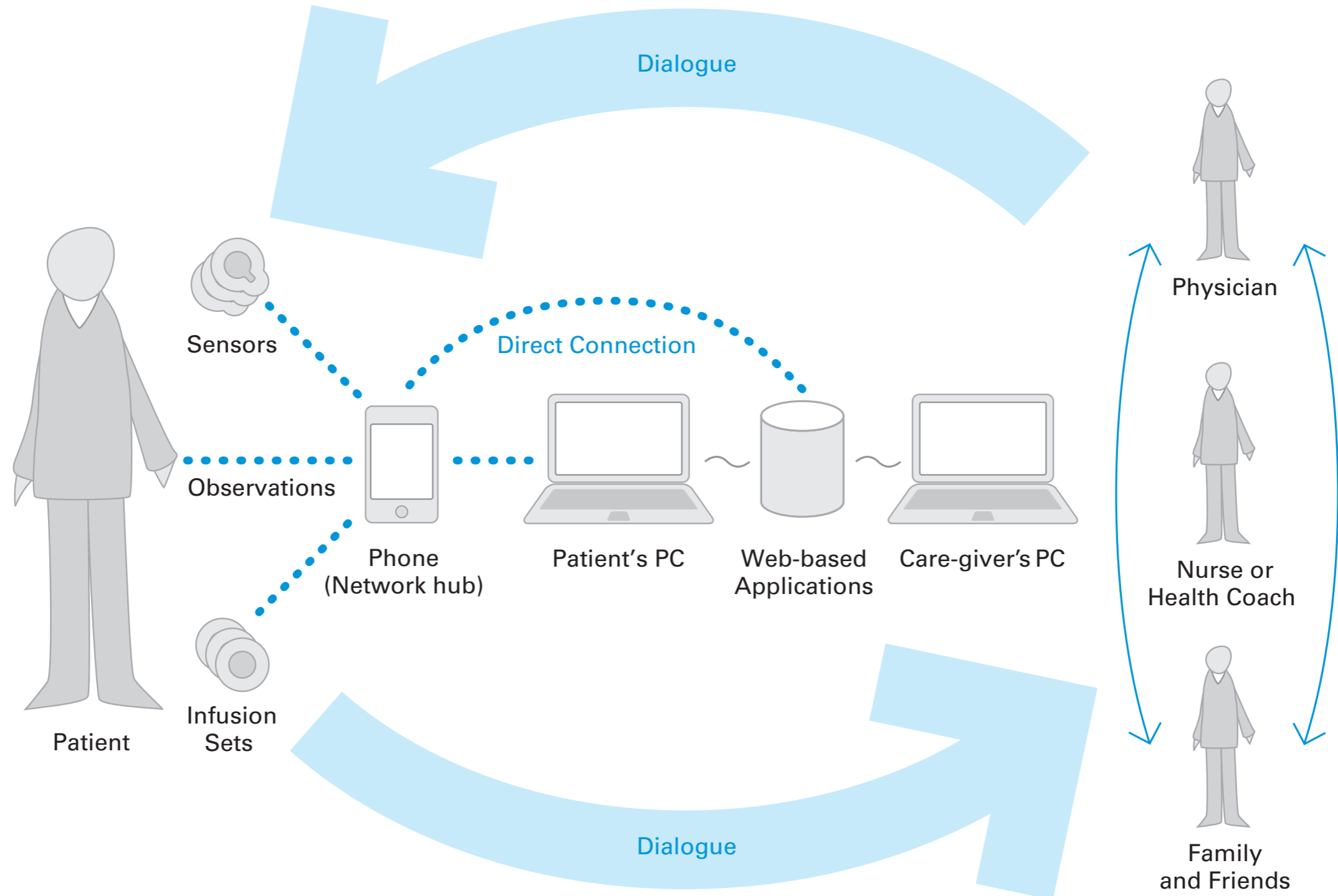
Implications for design

A billion little experiments: each of us figuring out what's working for us now



trial and error \approx
experiment \approx
quality management \approx
 \approx design

An enabling infrastructure: sensors+big data+services



**As you
design / market / deploy
self-management
technologies ...**

Questions to ask yourself

People focus on life, not health

Are you framing the problem broadly enough?

- Understand full context of person's life, not just the micro-activity (e.g. taking a pill, recording weight)

Is your system alleviating or increasing the user's workload?

- Minimize bio-cost of initiating and using self-management tools

Whose needs are you addressing first and foremost?

- Appreciate centrality of self-directed goals; user as final authority of personal goals and deciding "what's best"

Health is multi-factorial

How well are you addressing the user's unique situation?

Is your system supporting all key factors, including non-medical factors?

- Design flexible frameworks, customizable by users to their own needs
- Accommodate, don't dictate, user's choice of tools, therapies, interests
- Enable people to design their own well-being

Health is dynamic

Is your system meant for on-going or episodic use?

Is it designed to evolve?

- Design for ongoing, constantly changing, tiny self-experiments
- Support control and tracking of non-experimental variables

Continuous learning enables continuous adjustment

To what extent does your system support self-learning?

- Provide auto-analysis of user's own health experience over time
- Support user self-analysis (e.g. visualization)

How does your system enable learning from others' experience?

- Support learning from "others like me"
- Support auto-identification of "others like me"

Special thanks to: Hugh Dubberly, Paul Pangaro & Shelley Evenson

Full paper at: <http://bit.ly/ReframingHealth-Paper>

Also: “A Billion Little Experiments” <http://bit.ly/BillionExperiments>

Rajiv Mehta

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