

2018



Patient-Centered
Clinical Decision Support
Learning Network

www.pccds-ln.org

One Patient's Point of View



**DANNY VAN
LEEUWEN**

*Empowering people as
they travel together
towards best health*



Agency for Healthcare Research and Quality
Advancing Excellence in Health Care

About Me

An action catalyst **empowering people traveling together toward best health, wears many hats** in healthcare:

- **patient** with Multiple Sclerosis,
- **care partner** for several family members' end-of-life journeys
- a **nurse** for 40 years
- an **informaticist**
- a **QI leader**
- a **mentor** to leaders and advocates
- A **patient/caregiver activist**

Writing, speaking, and advising on learning what works for people in their health journey: informed decision-making, patient-centered research, communication at transitions of care, and technology supporting solutions created by and for people.

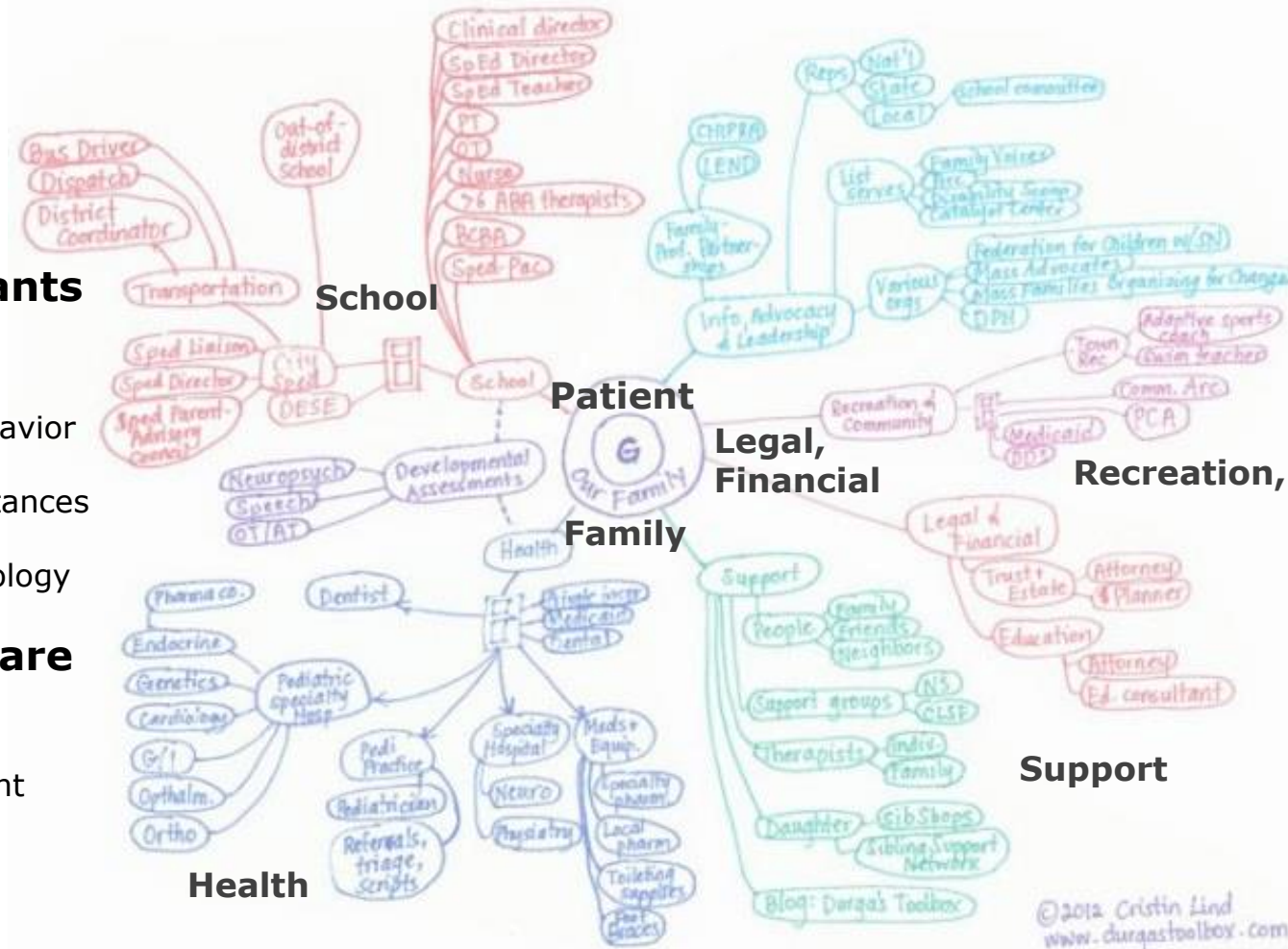


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Care Map

Info, Advocacy, Leadership



Determinants of Health

- Individual Behavior 38%
- Social Circumstances 23%
- Genetics & Biology 21%

Medical Care 11%

- Physical Environment 7%

Recreation, Community

Support

To Read the Care Map in more detail, go to Health-Hats website:
<https://www.health-hats.com/pccds-In-annual-meeting-2018/>

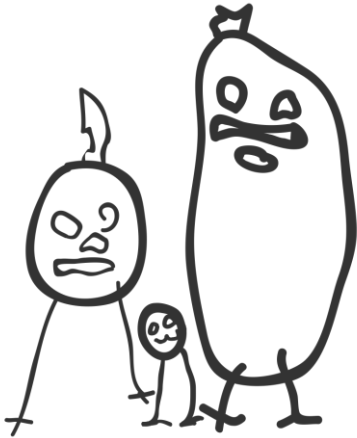
Decision Making



Choices

Informed

Shared



Fundamental to Making Decisions

- Decisions take **time**
- Many decisions occur **outside** the office and away from the bedside
- A decision is just the **beginning**
- Clinical decisions are made in the context of a **trusting** relationship
- Decisions imply a balance of **power**
- Grease or sandpaper? **Technology** is not a substitute for time and relationship

People Need Information to Make Choices

*I'm the child, Custodian and Healthcare Proxy of my 89-year-old mother, Alice. I live in a different state. My mother has diabetes and is depressed. Her **care team**, besides herself and me, includes medical providers in various health settings, community support agencies, and a full-time caregiver that helps her **schedule** and get to health-related services. My problem is to understand what my mother **wants for herself** and to **track who** says they're doing something for her (including my mother and me), **what** they're doing, and **when** they're doing it. I want to know **what it takes** to do it (Can she afford it? Can she get there? Does it agree with her? Who will be with her? etc.). I want to know if the **actions have the effects** we thought they would. I want to know what her **risks** are and how we plan to **prevent or respond** to them. I want to be able to keep **track** of all this and **keep it current**. I want to **share it** or have it shared from **day-to-day** and from **setting to setting** even if I'm not present. I want **answers to my questions** about what's going on and how she's doing when I have them.*

Information People Need to Make Choices

- Care Team
- Personal goals
- Plan Who, What, When
- What does it take?
- Did it work?
- Risks – Prevent and Respond
- Up-to-date tracking
- Share day-to-day, setting to setting
- Answer questions when we have them

Personal Data + Evidence

CDS Five Rights

- ✓ Deliver the right information
- ✓ To the right people
- ✓ Through the right formats
- ✓ Via the right channels
- ✓ At the right times

Thanks to Jerry Osheroff

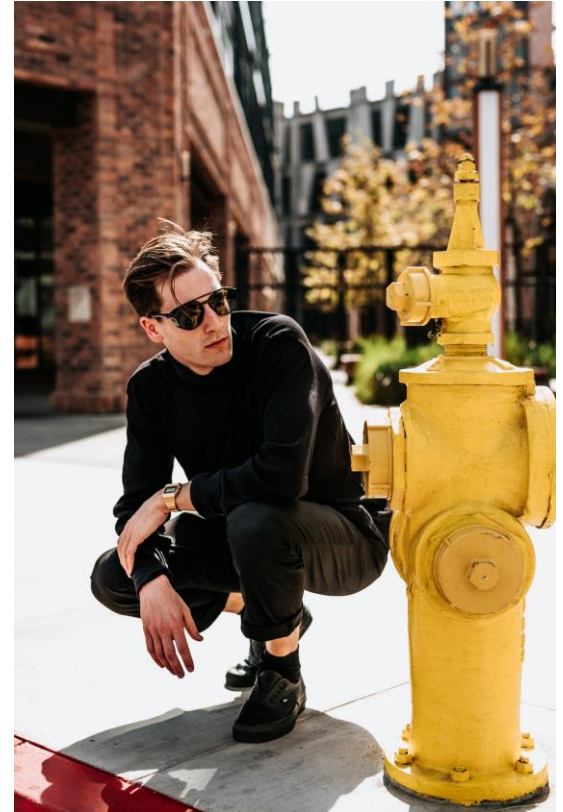
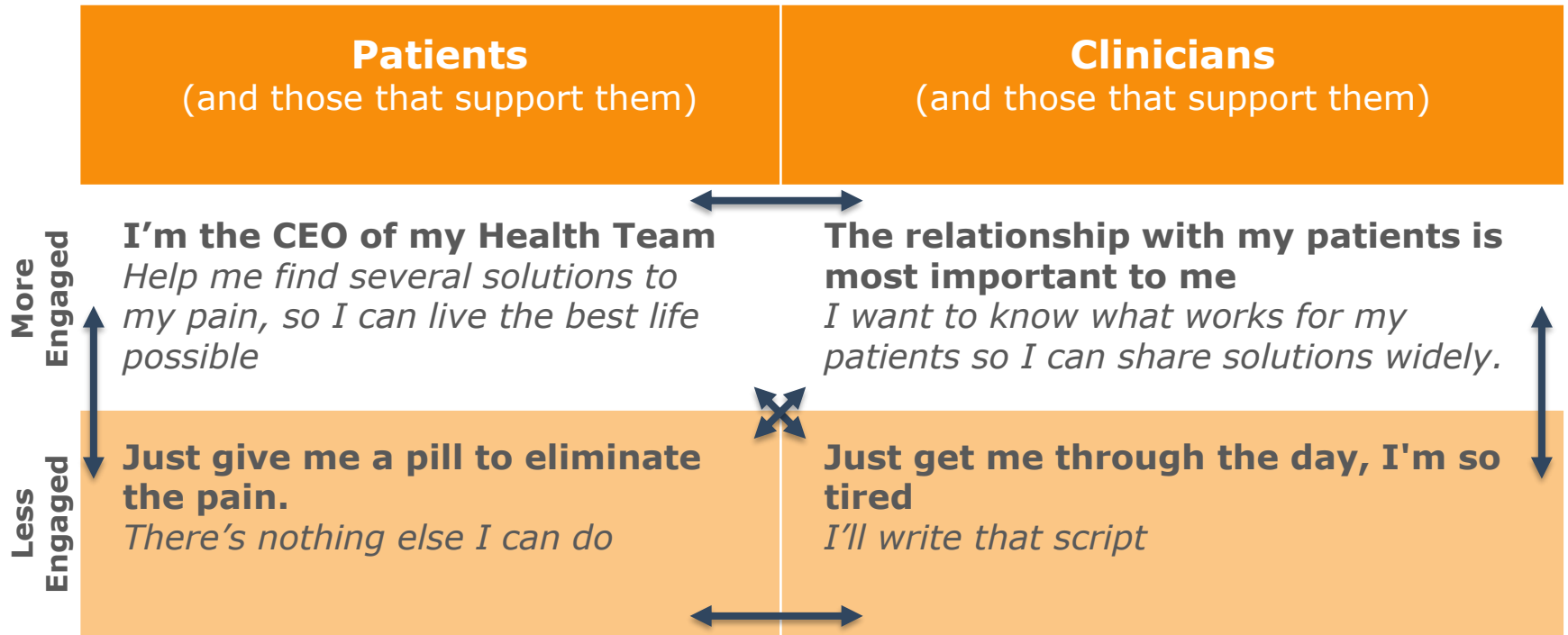


Photo by [Tyler Nix](#) on [Unsplash](#)

One Size Does Not Fit All People at the Center of Care Vary



Advice From Patients Making Health Choices

- **Imagine** that you have **all the information** you need to make decisions about your medical treatment including cost of those choices.
- **Imagine** that you can talk about your **life's goals and challenges** and that your doctor can hear you.
- **Imagine** that you have **time to talk** and share with your doctor without distractions.
- **Imagine** that your doctor **trusts you to be the expert** about you.
- **Imagine** that you have a **care partner** who goes to doctor visits with you, listens and advocates for you.
- **Imagine** that you have **access to medical advice** and can get questions answered when you need it, in a manner that you can digest.
- **Imagine** that if you try something and it doesn't work, you can **adjust quickly** with your health team to try something else.

Advice from Patients Managing Pain

- Discuss **pain goals and concerns**, including financial & emotional
- **Describing pain** is frustrating and limiting
- Use **palliative care** experts
- **Compensate providers** for pain decision discussions
- Refer to **local non-medication** resources
- **Pay post-op patients** \$200 to spend on a Pain Plan approved intervention if they don't fill an opioid prescription.
- Give a **list of evidence based non-pharm options** to every pre-op patient, and with every new opioid script
- Refer patient to **integrated BH support** to address coping skills
- Design usable pain **eJournal**
- Pain management is a **continual experiment**. Nothing works every time you're in pain, including medication

WHAT WORKS FOR PAIN



CURE

SURGERY, TIME,
WEIGHT LOSS,
DISEASE TREATMENT

- Treats the underlying cause of the pain and not just the symptom
- Can sometimes permanently eliminate the pain
- Expensive
- Invasive

Ideal for when the underlying cause of pain is threatening to overall health

SUPPLEMENTS

ORAL: MAGNESIUM, TURMERIC,
DEVIL'S CLAW ROOT, BUTTERBUR,
BOSWELLIA, OMEGA-3 FATTY ACID
TOPICAL: CAPSAICIN/CAPSICUM,
ANALGESIC CREAM, CAMPHOR,
MENTHOL, COMFREY

- Very few side effects
- Often require long term use
- May be condition-specific
- Research often scant
- Need to check for interactions

Ideal for chronic pain and inflammatory conditions.

PHYSICAL TREATMENTS

VIBRATIONAL CRYOTHERAPY, MASSAGE, ICE,
HEAT, ACUPUNCTURE, YOGA, FOAM ROLLERS,
MECHANICAL TAPE, TENS UNIT, SWIMMING,
POSITIONING PILLOWS, ULTRASOUND, HOT
SHOWERS, COMPRESSION, ALPHA WAVES,
STRETCHING, TRIGGER POINT DEVICES,
BATHS, WEIGHTED BLANKETS, ORTHOTICS

Ideal for acute pain, healing from an injury or surgery, and many chronic pain conditions

- Variety of options to fit lifestyle & budget
- Non-invasive, non-addictive
- Can be combined for greater results
- Varying levels of proven effectiveness between different treatments
- May take time and experimentation to find right fit

MIND + BODY SOLUTIONS

MEDITATION, EMOTIONAL SUPPORT, PUZZLES, HUGS,
SUPPORT GROUPS, PERSONAL FAITH PRACTICES,
MUSIC, COOKING, DANCE, VIDEOS, HIKING, GAMES,
MUSEUMS, SETTING AND ACCOMPLISHING ACTIVITY
GOALS (ACT), PROGRESSIVE MUSCLE RELAXATION,
COGNITIVE REFRAMING, DEEP BREATHING, AROMA
THERAPY, CALM AMBIENCE, GUIDED IMAGERY

Ideal for chronic and acute pain in combination with physical treatments

- Sustainable treatment for chronic pain
- Fosters support systems
- Nearly infinite variety of distractions
- More effective than traditional pain therapy for some types of chronic pain
- Requires a difficult mental shift in thinking about pain

Not all treatments or supplements are appropriate for all pain conditions. This list contains evidence based interventions and physical therapy options evaluated by MMJ Labs which may not be appropriate for every pain condition. Check with your physician to determine optimal recommendations.

Some people want drug free relief

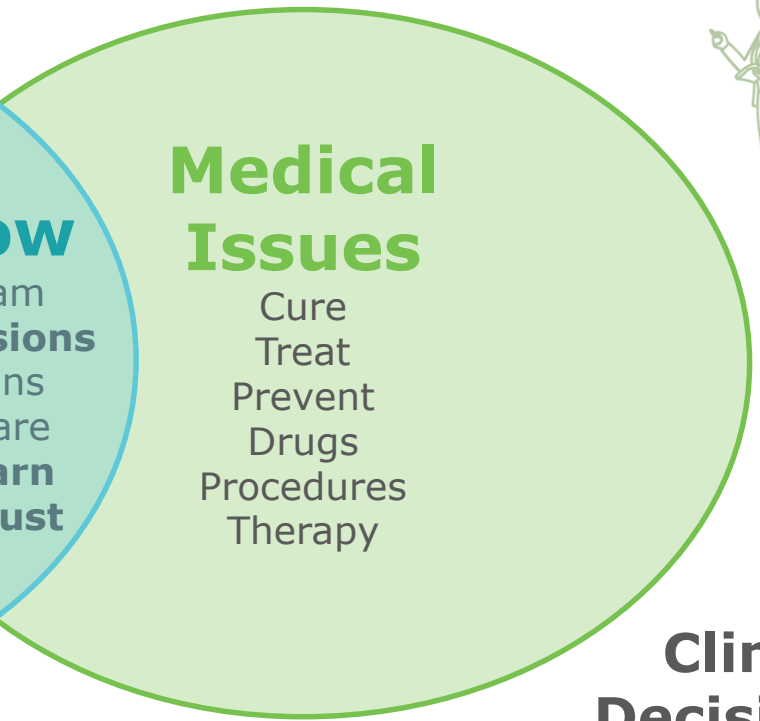
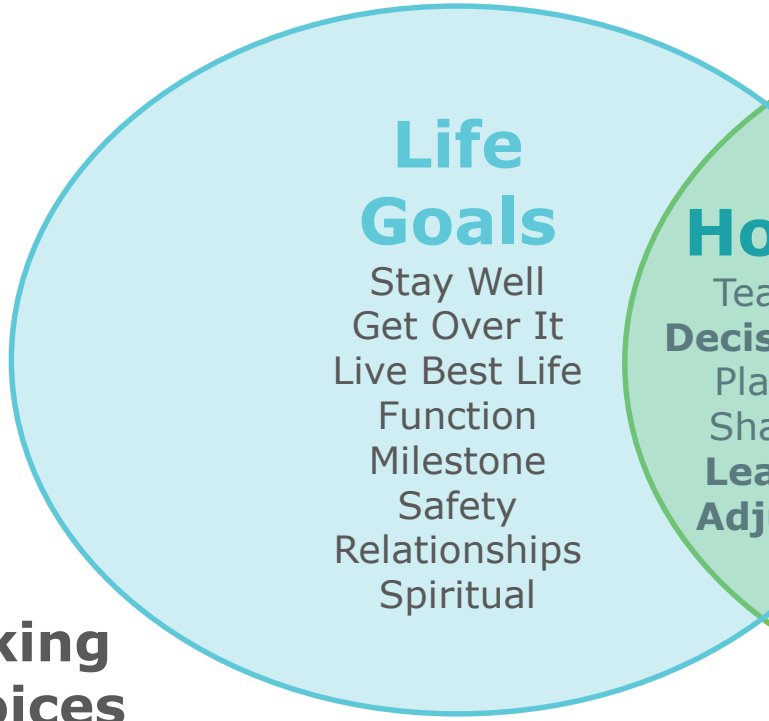
Where is the evidence?

Some want a silver bullet

Expertise and Evidence

Patient Expertise

Research-Based Evidence



Making Choices

Individual Behavior
Social Circumstances
Physical Environment

Clinical Decisions

Medical Care
Genetics and Biology

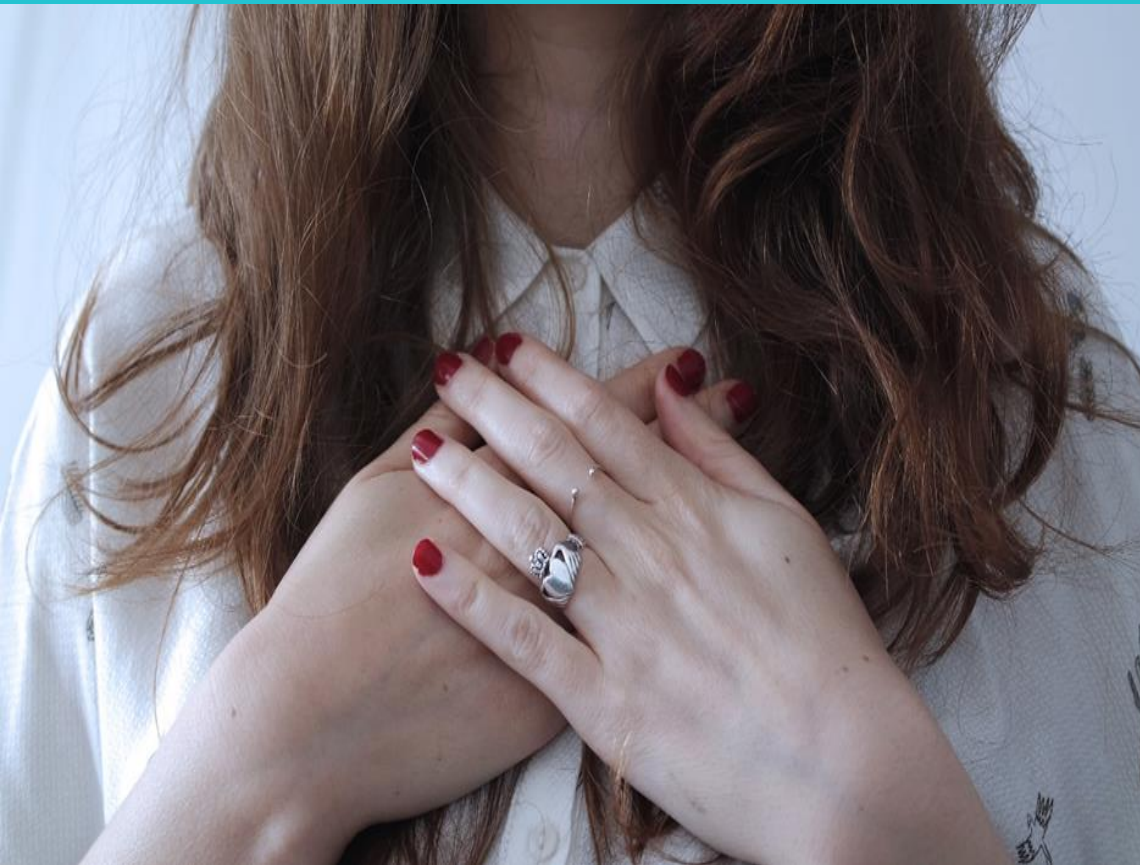
What does the CDS Industry Need to Do?

1. **Step out** of the clinical, academic, technology frame
2. Promote **time** for and **trust** in clinical relationships
3. Listen for and study **non-medical, non-biological solutions** that work for somebody
4. Influence those allocating \$\$ to pay for **non-medical, non-biological solutions**
5. Everyone at the Center of Care needs **just-in-time information**
6. **Invite** people at the center of care to sit at the tables of governance, design, operations and learning
7. **Design for variation** in people, life flow, and workflow
8. **Enable** personal, clinical, and technological **continual learning**

You have all experienced pain.

What would **you** want your professional selves and colleagues to know as they design pain management clinical decision support?

THANK YOU



MORE RESOURCES:



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[https://www.health-hats.com/pccds-
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