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**The Rules in Our Heads**

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**+** **What Do We Desire in Long Term Care?**

Quality of Care – FOR SURE!

That's what we are there for, isn't it?

But, there is Quality of Life and Autonomy and Choices

These are valuable and are also sections of the regulations for nursing homes

The issue: How do we optimize both?

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**+** **Culture Change Movement is Changing Things**

- Many homes are working hard to optimize autonomy – empowering residents to:
  - Get up and go to bed when they want
  - Choose what they eat
  - Choose to do things that have RISK!!!!
- How do we honor choices and also maximize safety?

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**+ More Opportunities Causes More Dangers, and More Worries for Us**

- What we decide we want to care plan for a resident is based on our education and experience
- But many nurses in LTC only have experienced a place that is locked down with few opportunities for choices
- Simple things people do at home may seem too dangerous for us to allow – how do you react to these?



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**+ What Happened to Us?  
We Used to be Wild and Free!**



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**+ Now we are Tame and Safe**



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**+ How did this happen to American culture?**

- Did I just grow up, or did we change?
  - Helmets and knee pads to play
  - Supervised play dates
  - Life in a calendar book
- How does this apply to a nursing home?
- Are we guided by worry?



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**+ But was I really wild and free as a child?**

- Not in all ways
  - Had to go to school
  - Had to do homework
  - Had to do chores
  - Sat many nights at dinner table when I would not eat my vegetables



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**+ Nursing Home is Not a Ship at Sea, It is Part of American Culture**



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+ In the nursing home, we are far closer to SAFE, can we move back toward the middle, to the balance point that maximizes both?



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+ The problem is “In loco parentis”

- I know what is good for you
- Our societal values have moved toward more safety, and we bring those values to work
- Safety is only one part of “in loco parentis.” We think we need to decide what is good for everybody and give it to them

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+ What do we value, really?

- Safety? Freedom?
- Doing our jobs?
  - What is our job, really – to keep people safe, keep them from dying, restrict them for their own good? Or to help them be as free as possible, have as much choice as possible?

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**+ Maybe we need to be more clear about “safe” and “free”**

■ We want our residents to be safe from what?

■ We want our residents to be free to do what?

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**+ What do we want nurses to learn in school?**

■ This balance of safety and autonomy and how to determine what to do – it is different in a hospital and in a nursing home or other long term setting

■ Autonomy becomes more important in long term care as that is where you live

■ Key is to individualize based on the specific resident or client, and based on what we value

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**+ “Not Tonight”**



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**+ Care Planning Rules in Our Heads**

- Team and doctor select the diet that is “best” for the person, based on diagnosis
- Resident needs an alarm on bed and another on wheelchair, as she tries to get up, and has fallen
- Give thickened liquids, as this person has a history of choking
- Limit smoking and alcohol

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**+ Let's Clean the Closet of Rules in our Heads**

- Doesn't mean throw everything out
- But look closely, keep some, throw some away
- Hmm, can't decide about some? Talk to a friend, discuss with a colleague, ask your mother, how does she want it

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**+ But . . . .**

- Many factors and players take part
- CMS regulations
- Nursing license, duties and values, MDS and Quality Measures and 5 Stars, doctor's orders
- And, of course, the survey process and deficiencies
- Surveyors were trained in the same clinical ethos as nursing home clinicians
- We need to tackle this issue by issue

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**+ We Are Making Progress – Bit by Bit, Issue by Issue**

- CMS/Pioneer Environment Symposium led to changes in Life Safety Code
  - Chair groupings in hallways
  - More decorations on walls
  - Gas fireplaces can be lighted
  - Lessening of restrictions in kitchens serving small groups of residents



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**+ How Did That Happen?**

- The Life Safety Code is developed by panels of engineering experts
- They were thinking FIRE, FIRE, FIRE
- EGRESS, SHELTER IN PLACE, SIGNAGE, ETC.
- They were unaware of how the LSC diminished quality of life



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**+ They Came, They Spoke, They Listened**

- We got to know the LSC people and inspired them with stories of outcomes to residents
- They got the point and changed the Code and they are now working on more changes
- It took 2 years
- Now 15 national task forces are working on standards, LSC, building code, many more codes



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**+ CMS/Pioneer Food and Dining Symposium**

- Led to a national workgroup that recommended changes in standards of practice for therapeutic diets
- Twelve groups that set standards of practice for food and dining, and therapeutic diets, and tube feeding, etc. worked together for several months
- Group reviewed research that showed very little benefit for older adults of restrictive diets.
- Much worse problem – when people don't like their food, they lose weight



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**+ The New General Standard for LTC**

- All persons moving into LTC should receive a regular diet unless there is a **STRONG** medical historical reason for a restricted diet.



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**+ The Diet Changes**

- Eliminate diabetic diet, cardiac diet, low sodium diet – default to regular diet for older person who is stable
- Research has shown very little benefit of these and a big problem of weight loss when people don't want their diets



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**+ Changes (Continued)**

- Eliminate thickened liquids
  - There is little to no long term evidence that use of thickened liquids prevents aspiration pneumonia, and there IS evidence that this can cause dehydration
- Eliminate pureed diet
  - Swallowing abnormalities are common but do not necessarily require modified diet and fluid texture. Provide foods of consistency and texture that allow comfortable chewing and swallowing



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**+ Changes (Continued)**

- Eliminate most tube feeding
  - Tube feeding does not ensure comfort or reduce suffering, it may cause diarrhea, abdominal pain, and it can increase risk of aspiration
  - Feeding tubes have not been shown to reduce aspiration or prolong survival in residents with end stage dementia



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**+ Changes (Continued)**

- Use real foods first
  - Fresh vegetables and fruits rather than supplements
  - Homes eliminating supplements “have found significant increase in food consumption and reduced incidence of weight loss”
- Honor choices, mealtimes, what to eat, support rather than restrict, make food available 24 hrs/day



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**+ Last One - New Negative Outcome**

- Mealtime dining studies show that enabling residents to choose what they want to eat DOES NOT RESULT IN NEGATIVE NUTRITIONAL OUTCOMES
- When a person does not want to follow diet orders (or any orders) we worry about potential harm. But we haven't contemplated the harm to the person from denying choices. No one should be told "you can't have this because it isn't on your diet."

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**+ New Negative Outcome - Continued**

- Denying foods of choice and sneaking in decaf instead of real coffee, is an assault to quality of life
- Making choices should not be called "non-compliant" or going "against doctor's orders" as if the practitioner is right and the resident is wrong.
- Taking away choice has been shown to hasten death, and also to deprive people of good quality of life, practitioners should adapt to residents, not the other way around

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**+ Back to our Rules:**

- All these changes impact the rules in our heads
- Do the rules in our heads of what is good to do need updating?
- Can we spring clean?
- There are many more issues that have not had national consensus yet
- KEY ROLE HERE FOR RESEARCHERS TO TELL US HOW MUCH SAFETY WOULD WE LOSE IF WE DO X, Y, AND Z

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**+ Spreading These New Thoughts**



- How do we let go?
- How do we explain it?
- Restriction is part of American culture
- Every professional, resident, family member can recite the restrictions.



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**+ Don't Forget the Residents and Families**

- "My doctor has told me for 20 years I have to check my sugars 4 times a day."
- "My mother can't have cake, she has diabetes."
- "I want you to do everything possible to keep my dad alive, give him the surgery."
- CHANGES TAKE MARKETING, EDUCATING, CONVINCING, SHOWING GOOD OUTCOMES



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**+ Surveyors Will Want Home to Show**

- How home found out what the preference is
- their efforts to educate a resident about a risky choice
- their efforts to care plan to mitigate bad outcomes from that choice
- Their monitoring of outcomes and continuing resident choice – did they want it but now don't want it?



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**+ So How Do We Move Forward?**

- Each issue is complicated; takes time, takes gathering of the national players
- At State level, momentum can be generated by state organizations gathering together to foster an idea
- At level of the nursing home, staff can have concerns about letting go of previous views and values

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**+ The Key to the LSC and Dining Changes**

- Generating momentum – having a big meeting
- Getting people together from stakeholder organizations to talk about what to do
- While together, they get to know each other and find commonalities
- Group finds areas they can all support
- The change is incremental – we can change these few things now and talk about the rest later.

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**+ It Takes Figuring Out Who is in Charge of Current Rules**

- Not always CMS, could be State regs
- Could be international building code people, Food Code
- LSC committees and fire marshals
- Universities that teach clinicians what to do
- Now that dining standards are changed, how do 15,000 homes implement?

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**+ Current Progress on Liberalizing Dining**

- In December, 2012, CMS released a 20 minute surveyor training video introducing these new dining standards, as something surveyors should support
- Pioneer Network has a current project to help nursing homes implement these standards – they are developing policy and procedures and tools – should be done 12/13

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**+ SO ....**

- WHAT DO YOU WANT TO CHANGE?
- WHAT NEEDS RESEARCH SO WE HAVE EVIDENCE THAT GIVES US COURAGE TO LIBERALIZE A "RULE?"
- HOW DOES ALL THIS IMPACT EDUCATION AND THE LICENSURE TESTS?
- HOW DO WE KEEP UP TO DATE?

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