How Many Shades of Gray?

Sexuality, Dementia and Long Term Care
Jane Marks, CDP
Or – Eeeeww or OK???
Surveyed individuals age 45 to 85 in their own homes.
Baby Boomers

Leading Edge Boomers, 1947-1956
Trailing Edge Boomers, 1957-1966
Well established in careers, hold positions of power.

Large majority of major law firm leaders and corporate executives are boomers.

Nearly 70% of law firm partners are boomers.

Like control

Invented overtime and the concept of “workaholic”
Values
Individual choice
Community involvement
Prosperity
Ownership
Self-actualizing
Health and wellness

Attributes
Adaptive
Goal-oriented
Focus on individual choices and freedom
Adaptive to a diverse workplace
Positive attitude
More highly educated
Witnessed and participated in some of the most important social change in history,
Civil rights movement,
Anti war campaigns
Women’s liberation
"At 74, I have never had such a fulfilling sex life. Often, when we make love, I see him as he was 30 years ago."

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So what did THEY say about sex??
83% DISAGREED that sex was only for younger folks.

25% said they had sex once per week.

21% of men over age 70 said they had sexual thoughts, fantasies, erotic dreams three times per week.

One in five say they engage in physical stimulation once per week.
Mr. Alvarez and Martha
Shortly after moving to the assisted living, Mr. Alvarez developed a relationship with another resident, Martha. Martha has early stage dementia, Mr. Alvarez does not.

Staff members were quite vocal about the relationship. One staff member said “I think I am marred for life, after walking in on them!”

One evening when he and Martha were “busy” Mr. Alvarez fell out of his single sized bed and broke his wrist! He then asked his daughter to get him a larger bed!

After a few weeks, Martha’s daughter began complaining about the relationship. She wanted it “stopped”. So, at night after both were settled in their own rooms, the assisted living staff began locking both Mr. Alvarez and Martha’s door from the outside. Mr. Alvarez’ daughter found out and felt that was dangerous and insisted they stop locking his door.

Staff then instituted a rule that “when one resident visits another resident in their room, doors MUST remain open.”
FLA Assisted Living Regulations:

Maintain a general awareness of the resident’s whereabouts. The resident may travel independently in the community.


Be treated with consideration and respect and with due recognition of personal dignity, individuality and the need for privacy.

Unrestricted private communication, including receiving and sending unopened correspondence, access to a telephone, and visiting with any person of his or her choice, at any time between the hours of 9 a.m. and 9 p.m. at a minimum

http://elderaffairs.state.fl.us/faal/consumer/resbor.php
Mr. and Mrs. Jones
Mrs. Jones was 76 and had Alzheimer’s. Her husband was 78 and her care had become too much for him, so he placed her in a nursing home.

Mrs. Jones loved to kiss and fondle Mr. Jones when he visited. One day, Mrs. Jones was quite amorous, and her room mate was at an activity. Mr. Jones closed the door of the room at the nursing home and lay on the bed with Mrs. Jones. They began to “have relations”. A staff person walked in to the room and was “appalled at what she saw.” She insisted Mr. Jones leave and the facility then filed charges, accusing Mr. Jones of abusing his wife.

Mr. Jones, who had been attending an Alzheimer’s Association support group, then contacted the Alzheimer’s Association for some advice and assistance.
Florida Nursing home regulations:

• A resident may associate and communicate privately with persons of his or her choice.

• A married resident shall be assured privacy for visits by his or her spouse.

• Make choices about aspects of his or her life in the nursing home that are significant to the resident.

But she has dementia.
Humans in general are not all that great at remembering facts. But we are good at remembering how to perform physical tasks.

Who was the U.S. President when WW I began??

What year did WW II begin?
We are very good with emotional memories.

Feelings, associated with people, events, places, music, smells
Sex has both an emotional memory as well as physical memory.
By eight weeks baby in womb can feel touch around his lips

Your hands and mouth have more nerve endings than other parts of the body.
### Physical attributes of the disease

**Retrogenesis* "Back to Birth"**

<table>
<thead>
<tr>
<th>Child Development</th>
<th>Acquired Ability</th>
<th>Stage</th>
<th>Alzheimer’s Disease</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td><strong>Stage</strong></td>
<td><strong>Lost Ability</strong></td>
<td></td>
</tr>
<tr>
<td>1 - 3 months</td>
<td>Can hold up head</td>
<td>Mild</td>
<td>No difficulty at all</td>
</tr>
<tr>
<td>2 - 4 months</td>
<td>Can smile</td>
<td>Mild</td>
<td>Some memory Trouble begins to affect job/home</td>
</tr>
<tr>
<td>6 - 10 months</td>
<td>Can sit up without assistance</td>
<td>Mild</td>
<td>Much difficulty maintaining job performance</td>
</tr>
<tr>
<td>1 year</td>
<td>Can walk without assistance</td>
<td>Moderate</td>
<td>Can no longer hold a job, prepare meals, etc.</td>
</tr>
<tr>
<td>1 year</td>
<td>Can speak with one word</td>
<td>Moderate</td>
<td>Can no longer select proper clothing for season</td>
</tr>
<tr>
<td>15 Months</td>
<td>Can speak 5 - 6 words</td>
<td>Moderate</td>
<td>Can no longer put on clothes properly</td>
</tr>
<tr>
<td>2 - 3 years</td>
<td>Can control bowels</td>
<td>Moderate</td>
<td>Can no longer adjust bath water temperature</td>
</tr>
<tr>
<td>3 - 4.5 years</td>
<td>Can control urine</td>
<td>Moderate</td>
<td>Can no longer use toilet without assistance</td>
</tr>
<tr>
<td>4 years</td>
<td>Can use toilet without assistance</td>
<td>Moderate</td>
<td>Urinary incontinence</td>
</tr>
<tr>
<td>4 - 5 years</td>
<td>Can adjust bath water temperature</td>
<td>Moderate</td>
<td>Fecal Incontinence</td>
</tr>
<tr>
<td>4 - 5 years</td>
<td>Can put on clothes without assistance</td>
<td>Moderate</td>
<td>Speech now limited to six or so words per day</td>
</tr>
<tr>
<td>5 - 7 years</td>
<td>Can select proper clothing for occasion or season</td>
<td>Severe</td>
<td>Speech now limited to one word per day</td>
</tr>
<tr>
<td>8 - 12 years</td>
<td>Can handle simple finances</td>
<td>Severe</td>
<td>Can no longer walk without assistance</td>
</tr>
<tr>
<td>12+ years</td>
<td>Can hold a job, prepare meals, etc</td>
<td>Severe</td>
<td>Can no longer sit up without assistance</td>
</tr>
</tbody>
</table>

* From “The Forgetting Alzheimer’s Portrait of an Epidemic” by David Shenk

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“Don’t run to call your neighborhood psychologist when your little girl rocks on her tricycle seat or your little boy puts his hands down his pants.” Instead, stop and consider why this subject makes you squirm. The very word “masturbation” gives many adults a deeply uncomfortable jolt, accompanied by heavy doses of guilt. If a child pulls his ear or strokes his arm, no one notices. So why do parents ignore the little boy who pulls his ear but worry and scold when he pulls his penis? It’s either because genitals are considered bad, mysterious, or off-limits, or they believe that genital rubbing is a sure sign of psychological disturbance. Neither of these are true.

Most children play with their genitals—expect this somewhere between age of two and six. The reason genital fondling bothers adults is that we tend to view children’s actions through adult eyes. To a child, masturbation is a normal part of discovering these parts of his or her body and the pleasurable feelings that come from them. In exploring their bodies, babies discover that some parts feel more pleasurable than others. Once these areas are discovered those little hands are frequently found there. To a child, massaging his or her genitals is pleasure. It is not “wrong” or “dirty.” Only if a child hears these terms from adults (or picks up on their anxiety) does he or she become worried and confused. "

Dr. William Sears MD, pediatrician and author of 30 books on child rearing.
Disease symptoms:

No filter.

Repetitive behavior

Cursing, yelling, walking, pacing
Behavior Management Goal:

• Address safety concerns
• Increase emotional well being.
Distraction...
Won’t work!!!
Competition might work!
The Busy Hands Fidget Apron
Fishsticks Designs

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Masturbating or having sex is a physical, tactile, energizing activity.

- Hitting
- Popping bubble wrap
- Walking
- Throwing a ball
- Batting a balloon
- Petting an animal
- Dry brushing

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Case Study:
Marion – 82 years old
Toilet tissue roll
“All great changes are preceded by chaos.”

Deepak Chopra
The call button
I'm young and I'm hot!
People need people.

The heart wants what the heart wants.
“Whatever makes him joyful.”
Family members

Staff members

Capacity and consent issues
In the case of an incapacitated person, the legal representative may refuse visits on behalf of the resident ONLY if the legal representative demonstrates that visits have a harmful effect on the resident.
Definition of MENTAL CAPACITY. 1 : sufficient understanding and memory to comprehend in a general way the situation in which one finds oneself and the nature, purpose, and consequence of any act or transaction into which one proposes to enter.
There is no bright line dividing those who are competent from those who are not. A person can be competent to make some decisions but not others.

For example, a person may be able to express her opinion about whom she trusts to handle her money, but not be able to fill out an income tax form. She may be able to decide she wants a flu shot, but not to decide which treatment is best for her breast cancer.

For example, a person in the early stages of Alzheimer’s Disease, or one with mental retardation or a head injury, may be able to tell a lawyer that she wants her sister to handle her financial matters, and to execute a legally binding power of attorney.

*The People’s Law Library of Maryland*

So to decide, you consider:

How complicated the decision is; whether it is consistent with the way the person has lived her past life; and how dangerous the consequences are..
Sexual Consent power of attorney
And another thing…

L G B T
• Health disparities among LGBT elders

• The IOM report detailed the following health needs and issues of LGBT elders:

• Transgender elders may experience negative health outcomes from long-term hormone use.

• HIV/AIDS affects older as well as younger LGBT individuals. However, few HIV prevention programs target older adults—a cohort that has been deeply affected by losses inflicted by AIDS.

• LGBT elders exhibit crisis competence (a sense of resilience and perceived hardiness)

• They experience stigma, discrimination, and violence across the life span.

• They are less likely to have children than heterosexual elders and thus less likely to receive care from adult children.
In 2011, two important reports were released. The Institute of Medicine (IOM) issued *The Health of LGBT People*, and The Joint Commission released a report about improving healthcare experiences for LGBTQ patients, families, and communities.

- See more at: [http://www.nursingcenter.com](http://www.nursingcenter.com)
AMDA – American Medical Director’s Association is dedicated to excellence in patient care and provides education, advocacy, information and professional development to promote the delivery of quality post-acute and long-term care medicine.

Clinical Practice and Policy:

By virtue of this White Paper, AMDA recognizes and addresses the need to provide ethical, responsible, and equitable treatment and quality care to LGBT and all other individuals in LTC.

AMDA will partner with the American College of Physicians (ACP), American Association of Family Practitioners (AAFP), American Medical Association (AMA), and other professional organizations fostering non-discrimination based on sexual orientation or gender identity.

AMDA will seek input on LGBT LTC issues from LGBT advocacy organizations including Services and Advocacy for LGBT Elders (SAGE), National Senior Citizens’ Law Center, National Center for Transgender Equality, Lambda Legal, National Gay and Lesbian Task Force, and others.
American Society on Aging
www.asaging.org
What do you think?

The Hebrew Home for the Aged in Riverdale New York

North of New York City near Yonkers.

www.sandwichcaring.com
Our goal is to provide care in a warm, homelike environment and in a manner, which preserves and enhances independence and dignity. Such care should be provided on the basis of a continuum of care in which older people can live, learn and flourish.

Our Values
In fulfilling its mission, The Hebrew Home believes in a person-centered philosophy of service, dedicated to:

- Celebrating our residents as unique individuals, deserving of dignity and respect;
- Fostering independence, meaning, comfort and personal choice throughout all aspects of life;
- Empowering our staff to support our residents’ choices;
A few years ago the Hebrew Home at Riverdale defied conventional wisdom and planned the ultimate field trip for residents. Dubbed the “Chutzpah Mission,” the group of residents ranging in age from 77 to 93, along with a doctor and a team of nurses and orderlies from the Hebrew Home, flew to Israel where they spent a glorious two weeks. It was a first ever overseas mission from a nursing home in the United States. Shown here are staff and residents in front of the Western Wall in Jerusalem. Now that’s living well!
Riverdale has a Sexual Rights Policy
World Association for Sexual Health established in 1978

Sexual rights are fundamental and universal rights.

World Association for Sexual Health (WAS) promotes sexual health throughout the lifespan and through the world by developing, promoting and supporting sexology and sexual rights for all. WAS accomplishes this by advocacy actions, networking, facilitating the exchange of information, ideas and experiences and advancing scientifically based sexuality research, sexuality education and clinical sexology, with a trans-disciplinary approach.
Your thoughts???