Focus 2019 Conference

Welcome Caregivers!

Madelyn & Quentin Wedding Photo - 1942

Honeymoon - Mt. Rainier
Three Don’ts of Dementia

Don’t Argue
You will not win

Don’t Try to Talk Them Out of It
They will not listen
Don't Pressure Them to Remember

Stolen memories do not get returned

Why We Need Written Policies

Bob & Dorothy
Bob & Dorothy

Bob & Dorothy Caught in the Act

NO!!
GROSS!!!!!

Bob’s Son Demanded Separation
The Residents and Staff Were Upset

Bob & Dorothy’s Children Disagreed

Mom’s happy! I see no harm in it.

It’s disgusting. I want them kept apart!

Staff Couldn’t Keep Them Apart
Dorothy Was Brokenhearted

She Was Sad For the Rest of Her

Henry and Donna Lou - Age 72

Married in 2007
Two Years Later...

Donna Lou exhibits signs of dementia

2014 - Moves Her Into Memory Care

Donna Lou's Daughters Meet with Staff

They say, “No more sex for Mom!”
May 2014, Roommate Reports Sexy Sounds

Daughter Gains Temporary Guardianship

August 2014 - Donna Lou Dies
April, 2015 . . .

Henry is tried for 3rd degree sex abuse

April 22, 2015 - Found Not Guilty

Couldn't prove Donna was not capable of consent, or that they'd actually had sex

Jury Instructions:

A person lacks capacity to consent if the person was, “at the time of the sex act, mentally defective to the extent that the person could not understand the nature and consequences of the sex act, rendering the person unable to offer effectual resistance to the approach of persons who might take advantage of weakness”
Sexuality & Intimacy in LTC

Does this photo gross you out?

Get Over It!!!

Myths: Older Adults and Sexuality

Unable to perform

Physically unattractive, therefore, sexually

They are fragile physically & might harm themselves

Old people having sex is embarrassing & disgusting

Sex is only for the young and beautiful

Older people should get over it and forget about it
These Attitudes Scream

AGEISM!!!

Two-Thirds of People 65+

Will require some long-term care at home

Forty Percent of People 65+

Skilled Nursing
A Lot of Them Will Have Dementia

Many Will Still Want to Have Sex

What are Your Personal Wishes?

Instructions to healthcare representatives
What is Your Professional Policy?

When This Happens . . .

Staff walks in during a private moment . . .

Do They Freak Out?
No one person can make the decision for another person to have sexual relationships. Not a family member, not a power of attorney, and not a legal guardian. Sexuality is a personal decision—every person must be capable of deciding this for her or himself.

Source: Wisconsin Board on Aging and Long Term Care Ombudsman
Think About the Last Time You Had Sex

Did you have to get permission?

Did You Have to Clear it With the Kids?

Hey Son,
Your Dad and I want to have sex. You got a problem with that?

If So . . . You’re Doing it Wrong!

Sexuality is a basic human need and the choice to be sexually expressive is one that belongs to the individual.
Dementia-Related Diseases & ISBs

- Huntington’s Disease
- Traumatic Brain Injuries
- AIDS Dementia
- Alcohol Dementia
- Wilson's Disease
- Creutzfeldt-Jakob disease

Source: “Sexuality & Dementia” by Douglas Wornell, MD

90% of Sexual Behaviors are Related to:

- Alzheimer’s Disease
- Strokes: Vascular Dementia
- Parkinson’s Disease
Types of Abnormal Sexual Behavior

- **Relationship issues:** Anxiety, paranoia, memory loss
- **Inappropriate behavior:** Normal sexual activity but abnormal for the situation
- **Hyper-sexual behavior:** Excessive preoccupation with sexual fantasies or urges

Source: "Sexuality & Dementia" by Douglas Wornell, MD

Alzheimer’s Disease

Loss of executive function

Everything is Either a Threat . . .

That they must escape
Or an Intense Desire . . .

That must be fulfilled immediately

Like Alcoholics . . .

Social inhibitions go out the window

Strokes

Personality changes, confusion, volatile emotions
Parkinson’s Disease

Excessive Dopamine

The More so Factor . . . Age Related

Source: Gero-psychologist Joseph Casiani

Dementia is an Identity Thief!
When Sense of Self is Disappearing...

I'm losing control!!! What's happening to me?

People Will Fight to Maintain Control

Personalities Become Amplified

Insecurities grow
Docile Person Becomes More Passive

Dominant Person Becomes Overbearing

The Hysteric

Becomes more hysterical
Needs to Create Drama

To get attention

The Obsessive

Has to be in control

As Disease Progresses

The obsessive needs to control EVERYTHING & EVERYONE
May Become a Hoarder

Focused on own needs & status

The Narcissist

Paranoid, jealous & suspicious
Narcissists Gets Angry

If they aren't center of attention

When Behavior Changes . . .

It could be a medical problem

Medications Can Cause . . .

Agitation and hyper-sexuality
It Could be Pain!

Urinary Tract Infection

It Could be Hunger
What Did Birdie Want?

What Did Danny Want?
What do Your Residents Want?

Are They Hyper-sexual?

Insistent, aggressive, or predatory

Craving Closeness & Connectedness?
Have They Lost Everything . . .

Except for their sexuality?

Sexual Behavior Isn’t Predictable

Just when you think you’ve seen it all . . .

Something happens that really surprises you

Here are Some Surprises

Married couple: Partner with dementia falls in love with someone else
Man in a Heterosexual Relationship

Mr. A

Mr. B

Becomes Sexually Attracted to . . .

Another man

Public Exposure

Who wants some of this?
Develops relationship with someone new

My Aunt Jean Did Not Approve!!!

Start at Admission

Learn as much as possible about the new resident
100 Things We Know About Mr. Brown

• Where was he born?
• What did he do for a living?
• What was his daily routine?
• Is he married? Does he have children?
• When does he like to take his shower?
• What does he like for breakfast?
• Would he rather read or watch TV?
• Does he love kids? Animals? Movies?
• What kind of music does he like?

What Was Their Sexual Relationship?

• What is this person’s gender?
• What are his/her sexual preferences?
• Does this person currently have a sexual partner?
• What was this person’s sexual life like before he/she developed dementia?
• Is this behavior different or unusual?
• Is this behavior causing problems?

Are ISBs at Home a Problem?
Have They Been Kicked Out of...

Other facilities?

The More Your Team Knows

The better prepared you’ll be to help
Help Family Members

Get over their embarrassment

Help Them Cope When Behavior Changes

And love becomes one-sided

The Person They Love is Disappearing

They are taking on more & more responsibilities and get nothing in return
Create a Lending Library

Books, videos, articles

Host a Support Group

Help Family Caregivers

ACCEPT - The disease is in control

UNDERSTAND - It is no reflection on them, their loved one, or their relationship

CHOOSE - Compassion, kindness & humor
Remember Madelyn

We Never Age Out of Our Sexuality

Companionship, intimacy & loving touch
Support for Caregivers

CaregiverHelp.com

Online Support for Caregivers

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