Sexuality and Intimacy: A Guide for Dementia Patients in Long Term Care and Home Care Setting

Prepared by Sandra Stimson CALA ADC CDP CDCM AC-BC
National Council of Certified Dementia Practitioner
www.nccdp.org

Permission To Copy

Thank You ILC

We want to acknowledge the ILC The International Longevity Center of the UK for allowing the NCCDP to utilize their hand out in developing this Power Point. *"The Last Taboo A Guide to Dementia, Sexuality, Intimacy and Sexual Behavior in Care Homes"*

Download the handout to be used with this Power Point.

Hand Out
Please See Your Hand Out

Thank you to the International Longevity Center UK in granting permission for the NCCDP to utilize this important document.

"The Last Taboo A Guide to Dementia, Sexuality, Intimacy and Sexual Behavior in Care Homes"

http://www.ilcuk.org.uk/index.jsp

Please see this web site to download the handout document

London UK Document

- Be aware that the handout was developed in the UK so some of the ACTS referred to in this document may not be the same in America.
- Example: Sexual Offence ACT 2003

http://www.legislation.gov.uk/ukpga/2003/42/contents

Wonderful Quote

"Young love is about wanting to be happy. Old love is about wanting someone else to be happy." Mary Pipher, Psychologist Pioneering Change: "Sexuality in Nursing Home"

Basic Human Need

Sexuality and Intimacy is fundamental to an individual and intrinsic to a person's self and well being.

At any age we require

- Companionship
- Intimacy
- Love

Definitions

- Intimacy *"A close familiar and usually affectionate or loving personal relationship with another person or group."*
- Sexuality *"Pertaining to copulation, having sex or involving sex, implying or symbolizing erotic desires, capable of sexual feelings."*

Source: World English Dictionary

and Dictionary.com

Mental Capacity

"Mental Capacity- Sufficient understanding and memory to comprehend, in a general way, the situation one finds ones self and the nature, purpose and consequence of any act or transaction into which one proposes to enter."

Source: Merriam –Webster Dictionary

Capacity and Competency
Dr. Reed
http://www.competence-capacity.com/

A basic principle is that the terms competence (or "competency") and capacity must always be qualified by the question "for what?" Capacity only can be assessed in relation to a specific demand or task. Areas of mental deficiency can leave a patient competent for one task, for example, for writing a will ("testamentary capacity"), but not for another, such as managing an apartment building.

Capacity

Capacity--In the context of geriatric psychiatry and forensic psychiatry, refers to the intact ability to respond to a particular situation with appropriate appreciation and to act in one's own self-interest.

continued

Capacity

A person may lack capacity for a number of different reasons: memory impairment (e.g. Alzheimer's Disease), inability to read or understand language (e.g. stroke), loss of brain functions related to judgment and planning and initiative (e.g. frontal lobe disorders), hopelessness and loss of self-worth (e.g. depression). A person with otherwise intact mental faculties may have capacity compromised by "undue influence." Dr. Reed

Partial Capacity or Diminished Capacity Definition

"Not complete or entire"

There are no clear cut definitions for Limited / Diminished or Partial Capacity

- The legal profession has it's own definition as it pertains to legal issues such as Power of Attorney.
- While the health care industry has it own interpretation of these words.

Center for Practical Bioethics
Tarris Rosell PhD Dmin

Full decisional capacity means that an individual has sufficient . . .

- *Knowledge with understanding (of relevant information, including risks and benefits)*
- *Voluntariness without coercion,*
- *Decisionality (ability to choose between options)*
- *Communicability (ability to communicate choices made) so as to be able to make all types of life decisions for oneself.*

Center for Practical Bioethics
Tarris Rosell PhD Dmin

Limited, partial, or diminished capacity means that an individual has insufficient knowledge, voluntariness, decisionality, and/or communicability so as not to be able to make some types of life decisions for oneself.

Capacity or incapacity is always in relation to the type of decision to be made.

Center for Practical Bioethics
Tarris Rosell PhD Dmin

- *Decisions involving higher risk and/or lower benefit require more sufficiency of knowledge with understanding and voluntariness without coercion.*
- *Decisions involving lower risk and/or higher benefit require less sufficiency of knowledge with understanding and voluntariness without coercion.*

Center for Practical Bioethics
Tarris Rosell PhD Dmin

Decisionally incapacitant means that an individual has insufficient knowledge, voluntariness, decisionality, and/or communicability so as not to be able to make any type of life decision for oneself.

Michael E. Salacz, MD
Medical Director, Saint Luke's Brain Tumor Center
Neuro-oncology Clinic

From a practical standpoint, I have found assessing capacity for decision making an important element of the physical exam of my patients with brain tumors. I have a number of folks who clearly don't have the "capacity for consent" – i.e. they can't do one or more of the following

Michael E. Salacz, MD
Medical Director, Saint Luke's Brain Tumor Center
Neuro-oncology Clinic

1) demonstrate an understanding of their medical condition

2) describe the decision to be made

3) relate the benefits and downsides of both the proposed intervention as well as the pros and cons of not doing the proposed intervention and, finally

4) give a logical reason why they are making the decision.

Michael E. Salacz, MD
Medical Director, Saint Luke's Brain Tumor Center
Neuro-oncology Clinic

However, many of these folks clearly retain the "capacity to assent" to a medical decision. For example, the patient who can't demonstrate the capacity to consent for surgery can still make it very clear that he/she does not want surgery. While, practically, the decision is still typically discussed with the DPOA or next-of-kin as the situation dictates, the patients voiced opinion is clearly important in the decision making process

Michael E. Salacz, MD
Medical Director, Saint Luke's Brain Tumor Center
Neuro-oncology Clinic

So, I would suggest that "limited" decision making capacity is that group of folks who don't possess the "capacity for consent" but do still retain the "capacity to assent" to a decision. The pediatric ethicists may have a formal definition of capacity to assent to medical decision making – I have heard this concept many times from my pediatric colleagues.

Limited Capacity

Limited capacity to process information…

"The inability to reason clearly as evidenced by such indicators as: being in a confused state of mind, the inability to recognize persons known to them, being disoriented as to place and/or time or severe memory impairment. "

Kevin Bress Esq.

Law Firm of Hodes Pessin and Katz

Decisional Capacity

Decisional capacity: *A clinical determination that an individual has the ability to understand and to make and take responsibility for the consequences of health decisions. Because capacity is not global but decision-specific, patients may have the ability to make some decisions but not others. Capacity may fluctuate according to factors, including clinical condition, time of day, medications, and psychological and comfort status. Source* http://consultgerirn.org/topics/treatment_decision_making/want_to_know_more

Incapacitated Person

Is an individual who is unable to receive and evaluate information or make or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health, safety, or self care even with appropriate technological assistance. Source

http://www.apa.org/pi/aging/resources/guides/judges-diminished.pdf

The Six Pillars for Guardianship

- In determining capacity for guardianship hearings judges consider the six pillars and determine this by **comprehensive assessments, observation and interviews**. Each case is unique and the finding form the framework in a decision.
- Medical Condition
- Cognition
- Everyday Functioning
- Values and Preferences
- Risks and level of supervision
- Means to Enhance Capacity

Judge Takes 5 Steps To Do This

- Screen Case
- Gather Information
- Conduct a Hearing
- Make a Determination
- Ensure Oversight
- http://www.apa.org/pi/aging/resources/guides/judges-diminished.pdf

Don’t Just Rely on Assessment Tools. Include the Following to Get a Clear Picture

- Observation (at minimum 6 hours)
- Interviews with staff, family and others
- Assessment Tools
- Involve Professionals
- If possible a team meeting to discuss findings

Many Assessment Tools To Consider When Conducting Your Evaluation

Function Assessment Tools

Cognition Assessment Tools

Communication Assessment Tools

Decision Making Assessment Tools

Sexual Competency Assessment Tools

Capacity Assessment Tools

- Psychiatric Assessment and Evaluations
- Emotional Assessment
- Risk Assessment / Considerations
- Sensory Function Assessment

Interviews Are Part of the Evaluations

- Resident Interview
- Partner / Family Interview
- Staff Interview

Patient History

- Medical History
- Social History

- A complete physical may also be required.

Capacity Assessment Tools

- ACE Aide To Capacity Evaluation
- CAT Capacity Assessment
- CCTI Capacity to Consent to Treatment Interview
- ILS Independent Living Scales

There are others

ADL / IADL Rating Scales

- AFABS Adult Functional Adaptive Behavior Scale
- DAFS Direct Assessment of Functional Status
- MAI Philadelphia Geriatric Center Multi Level Assessment Inventory

And there are others

Attention Tests

- WMS III Working Memory
- PASAT Paced Auditory Serial Attention
- DRS Dementia Rating Scale
- TRAILS A Trails Making Test
- Continuous Performance Test

There are others

Memory Test & Cognition Test

- MAS Memory Assessment Scales
- DRS Recognition
- FULD Object Memory Evaluation
- MMSE Folstein Mini Mental State Exam
- GDS Global Deterioration Test

And there are others

Communication Tests

- BNT Boston Naming Test
- Multilingual Aphasia Examination
- Verbal Frequency Controlled Oral Word Association Test

There are others

Dementia Care Mapping

- You can also use Dementia Care Mapping which is observation over a six hour period and documenting during that period observed behavior.
- A method designed to evaluate quality of care from the perspective of the person with dementia through observation and measurement.

- Assessments are just tools because it is not possible to give an exact test of capacity.
- Capacity is a professional, clinical and ultimately legal judgment.
- Source: http://www.apa.org/pi/aging/resources/guides/judges-diminished.pdf

Clinical Judgments

Article Capacity Assessment in the 21st Century

Clinical judgments of capacity can often be inaccurate, unreliable, and even invalid. Thus, capacity assessment training should become a part of the clinical training of physicians, psychologists, and other health care professionals working with the elderly population (+Karlawish & Schmitt, 2000; +Marson, Sawrie, et al., 2000).

Capacity Training

Have you had training for Capacity, Evaluation and Observation techniques and tools?

Assume They Can!

Assume they (patient) can make decisions for themselves until you have completed the full assessment, conducted interviews, observed the situation over 6 hours and involved the team of professionals.

Unless this is a dangerous situation than act immediately and report immediately!

Person Centered Care

Cornerstones of Person Centered Care

- Respecting a person's individuality
- Preserving their dignity

Fact

People with dementia who live in homes and LTC settings have among the most complex health and social care needs of any group in society.

Fact

- Do you agree that a resident sexual behaviors and your observations come with myths, taboos, personal beliefs, prejudices, negative attitudes and your personal attitudes towards men or women?
- Do you agree that little sexual and intimacy education is provided to staff?
- Often times there are no policy or guidelines to help you as staff to address concerns.

Fact

Many health care professionals responsible for the decisions of the patient have received little training specifically dealing sexuality.

This In Turn Affects Your Response

These are key factors that influences your response to a situation or perceived situation.

As a result their intrinsic rights is often

- Denied
- Ignored
- Stigmatized

The Need for Affection

Old Age or cognitive impairment does not erase the need for;

- Affection
- Intimacy
- Relationships
- Warmth
- Touch

No Hard and Fast Rules

- Each situation and *Each Resident* is Unique so your approach and assessment / evaluation or no approach or need for assessment / evaluation will be individualized for each person.
- Education in this area will help guide you.
- Development of company policies, assessment tools and evaluation protocol will help you as a team develop person centered care plans.

What is Acceptable Sexual Expression?

Evidence suggests that we are accepting of light forms of expression such as;

- Holding Hands
- Stroking
- Kissing

Other Forms of Sexual Expression Are Met With Different Emotions

- Concern
- Shock
- Outrage

Range of Patient Issues To Consider

- Autonomy
- Dignity
- Mental Capacity
- Safe Guarding
- Perceived Need to Protect

General Public Attitude

"Most people are not even willing to consider or contemplate that people with dementia may have intimate or sexual needs."

This is due to our own misconceptions, preconceptions and prejudice.

What Are Comments You Have Heard People Say About Old Age and Sexuality?

- Please take five minutes and divide up into groups and write down comments you have heard among your peers.

- Please tell me what are some of the labels you have heard to describe an elderly person?

Negative Comments

- “Old people are sexless”
- “I think it is gross if they kiss”
- “I am sure he is masturbating because he always has his hands in his pants.”
- “Sex is for younger people”
- “How do I know this is what they want?”
- “What will people think if we let them have an intimate relationship”?

“ I did not realize until now, but my reactions to men and women is quite different. When I see an older man with dementia touching an older women I do tend to get quite angry, whereas towards the older women with dementia I feel quite protective and maternal towards them.”

What is the Best Model To Use in a Health Care Setting?

- We moved from Medical Model
- To Social Model
- A Third Model is The Biopsychosocial Model

Medical Model or Social Model or Biopsychosocial Model (UK)

Medical Model USA and UK

- Focus on disease, disability and old age.
- Individual identity defined as dementia.
- Person infantilized (treated like a baby).
- Difficulties with care staff with regards to sexual expression.
- Person is passive and over protected by staff.

Social Model (UK)

- Emphasis on person Centered Care (USA).
- Know person history, health status and previous response to stress and personality.
- Social and environmental factors are considered.
- More liberal model of understanding of sexual expression.
- Person family, staff, partner and other residents considered.

Biopsychosocial Model

- A Third Model is The Biopsychosocial Model which it is called in the UK. In America we take this into account for “Person Centered Care.”

- This model looks at dementia in a holistic way and considers a range of factors, understanding of dementia, development of responses and interventions.

FACT

- Care Plans often do not address sexual needs of individual clients. (Wallace 2003)
- Need for human intimacy for most people, lasts until end of life. (Kuhn 2002)
- People in late stages may become less interested in sexual activity. (Bouman 2002)
- This does not diminish need for human affection, warmth and affection.

Fact

"Benefits of sexual expression and intimacy for older adults with dementia are often overlooked but the evidence suggests that they enhance general health and well being."

(Kuhn 2002)

Couples

Some couples may wish to continue to maintain a sexual relationship for a source of comfort, reassurance and mutual support.

What happens when only one partner has dementia and has entered the care home?

You Might See Possible Changes to a Couples Relationship When One Partner with Dementia

Remember you do not have a history of their relationship so you are basing your observations on what you are seeing right now. But you may observe;

- Awkward sequencing of sexual activity.
- Requests for activities not normally performed.
- Lack of regard or consideration for the sexual satisfaction or feelings of the healthy partner.

- Loss of sexual interest
- Increased sexual demands
- Inadequate sexual advance by the individual with dementia.
- Concerns over mental capacity.
- The dementia patient no longer recognizes their partner.

The Well Partner May Change As Well

- Loss of interest in intimacy because they see the dementia partner as sick.
- The well partner may now have formed a new relationship with someone else.
- The person with dementia may also have formed a new intimate relationship with someone other than the partner who is living in the care facility.

Friends, Family and Health Care Professionals

- You may be uncomfortable and reluctant to acknowledge or support the sexual aspect of their relationship.
- The relationship may need to be monitored carefully to ensure the resident with dementia has the mental capacity to consent to intimacy of a sexual nature.

How Can You Support a Pre-existing Relationship?

- Acceptance / Acknowledgement that older people with dementia have a need for intimacy and sexual expression.
- Promote a culture of acceptance, dignity and privacy. “Do not disturb signs”
- Provide education and awareness to workers and family / partner on sexual and intimate needs.

- Try to obtain the sexual and social history of resident for care plans. Don’t force the information because of the sensitive nature. Be matter of fact yet sensitive when you ask the questions.
- Be aware that not everyone is heterosexual. Educate and be sensitive to LBGT, Lesbian, Gay, Bisexual, Transgender, Sexual identity and Heterosexual.

- Encourage the relationship and visits to happen in and outside the care home.
- Promote privacy for couples to be together, either a designated room (if shared) or if a private room a sign that says, “Do Not Disturb.”

- Provide sexual advise or referral.
- Provide information and support for resident.
- Continue to monitor and assess in terms of resident with dementia and mental capacity.
- Observe for forced signs of intimacy such as bite marks, blood or tears or bruises in genital areas.
- Communicate with spouse /partner and or responsible party.

How To Ask About Sexual History

- Be matter of fact, direct and sensitive.
- Don’t make assumptions about sexual orientation, use the word partner instead of boy friend, girlfriend, husband or wife.
- Ask how many partners they currently have instead of are you married or monogamous? Ask are you sexually active?

Ask About Sexual History

Respect the patients reluctance to disclose everything about sexual history on the first interview. (Proactive Sexual Health History)

Ask About Sexual History

- Don’t be intrusive or ask unnecessary questions.
- Start with least intrusive questions first.
- Make sure patient understand the terms and language you are using and you in turn understand their slang or what they are trying to convey. Rephrase what they say in a professional manner.

Read The Stories in Handout

- Please take the time now to read Sheila and Bills' Story, Patricia and Elaine's Story and Norman and Marie Story.

- What are your thoughts on each story?

Forming New Relationships

What do you do when a married couple spouse with dementia wants to form a new relationship with someone else in the home?

Each staff's response will be unique to the person and situation.

Forming New Relationships

Staff and family responses will be determined by the nature of the relationship.

Cuddling or hand holding does not generally provoke a response by family or staff.

But What Happens When It's More Than Hand Holding?

When relationship appears more sexual in nature, several issues may / or will need to be addressed. But at same time keep in mind;

- Autonomy
- Preservation of dignity
- Competence related to informed consent
- Privacy
- Protection from harm

Remember

- People with dementia can make new relationships and intimate relationships.
- If a person with dementia can make decisions about their life than this should be respected.
- If, the resident is not physically or mentally vulnerable as a result of relationship, than consider ways to facilitate and support the relationship.

- It may be difficult to assess to the extent a resident has full mental capacity, partial capacity or limited capacity and so the team may have difficulty reaching a consensus or appropriate response.
- A resident may perform poorly on mental status test but his /her preference for the special friend is evident.

“There is not an All or Nothing Approach”

- Treat each situation as unique
- Treat each person as an individual

How To Determine the Capacity and Risk to The Individual

- To what extent are the residents involved capable of making their own decisions?

- Does the resident with dementia have the ability to recognize the person with whom they are having the relationship? Are they mistaking the person for their original partner.

Is the resident with dementia capable of expressing their views and wishes within the relationship through either verbal or non verbal communication?

- Can the residents involved understand what it means to be physically intimate?
- What is the residents ability to avoid exploitation?
- What is the resident's ability to understand future risks?
- How may the resident be affected if they are ignored, rejected after intimacy or the relationship ends?

Wider Considerations and Ethics

- Is the behavior in keeping with their past values, beliefs and or religious views?
- If the behavior is not in keeping, but the resident appears content and happy, to what extent should this matter?
- To what extent do care providers have the “right” to intervene in the sexual lives of people with dementia and what rights are denied when such interventions occur?

- To what extent should others be allowed to make decisions about the relationship of residents?
- How do you balance the safety of the residents while also empowering them to live their lives?

Nurse's Notes and Care Plans

- Nurses initial notes should clearly explain the situation and why you are evaluating. Include in the notes; Who What Where When and Why.
- After the evaluations and a decision is made the nurses notes should contain the conclusion and summary of concern and action or no action taken.
- A Care plan may need to be initiated.

Remember for the Comprehensive Evaluation You will Need

You may need Psychological Evaluation, Consent to Sexual Activity, Informed Consent, Staff Interview, Clinical Interview, Behavioral Observations (6 hours min), Review of Medications, Functional Capacity Assessment, Cognitive Assessment, Psychiatric / Emotional Assessment (American Bar Association)

What About the Family? Family Matters

- Are family, friends or partner aware of the new relationship? Should they be?

- If there is a partner living outside the care home, are they aware of the relationship and do you know how this will make them feel?
- Do you tell the partner?

- Does the family or partner feel comfortable in expressing their views about the relationship?

- To what extent should the views of family, partner, friends be taken into consideration if they are unhappy with the relationship?

Abuse

- If you suspect any form of sexual abuse take action immediately!
- Remove resident from risk.
- Protect and support the resident.
- Inform your supervisor immediately and follow facility protocol for suspected abuse.
- Report to the governing bodies for your state and in some instances report to police.

The Law Recognizes Three Factors That Must Be Analyzed in Determining Legally Sufficient Consent by the Patient

1. *Knowledge of the relevant facts relating to the decision to be made.*
2. *The mental capacity to realize and rationally process the risks and benefits of engaging in sexual activity.*
3. *Voluntariness, meaning the absence of coercion and the presence of a realistic choice between engaging or refraining from activity.*

Source: Assessment of Older Adults with Diminished Capacity

Regardless of the legal standard, an even greater challenge is the lack of a clear standard for the assessment process, i.e., the evaluative criteria and tools to be used in the assessment of capacity to consent to sexual relations.

Source: Assessment of Older Adults With Diminished Capacity

Ethic's Committee

- Report the concern or incident to the Ethic's Committee for your facility.
- You may need to involve the county or hospital ethic's committee if your company does not have one.
- Each situation is unique but the very nature of incident may raise some complicated ethical and legal issues.

Individual Sexual Behavior and Expression

Reasons for sexual disinhibition or inappropriate behavior *may* be linked to;

- Disease related factors
- Social factors
- Psychological factors
- Certain medications, illicit drugs and or alcohol
- Today the reasons are unclear and more research needs to be done.

What Does Research Say About Dementia and Sexual Behavior and Expression?

- It is not particularly common. (Higgins 2004)

- More likely to occur in severe stages of dementia. though sometimes evident in persons with mild cognitive impairment.
  (Alagiakrishnan 2004)

- Staff, resident and family disagree on what is meant by appropriate or inappropriate behavior. (Gibson 1999)
- Some studies state that it is of equal frequency of inappropriate behavior in men 8% and women 7 %.
- Men's behavior may be over reported vs. women's behavior.

How Do We Categorize Sexual Behavior?

There are no hard and fast rules when it comes to assessing sexual behavior and responses and there is no particular definition as when the behavior becomes abnormal. (Manchip and Menon 2007)

Verbal Sexual Behavior

Verbal

Sexualized comments to staff and others.

May include swearing

The following may or may not constitute abnormal sexual behavior.

- Sexual disinhibition
- Inappropriate Behavior
- Improper behavior
- Hyper sexuality

Remember your beliefs, attitudes and values will affect your response or judgment.

Physical Behavior

- Masturbating in private
- Masturbating in communal areas
- Touching in private
- Touching in communal areas
- Undressing or disrobing / exposing genital areas
- Defecation or urination

Physical Actions Linked To Others

- Prolonged kissing & hugging that exceeds normal affection.
- Touching or grabbing personal parts of a member of staff or another residents body.
- Attempting intercourse or oral sex with staff or resident.
- Attempting sexual acts with objects. Not to be confused with sex toys.

What Is The Culture of Your Home?

- Staff responses will also be determined by the culture and ethics promoted within the care home and individual circumstances involved.

- The frequency and location of the behavior will also be important when making decisions.

- “One older gentleman with dementia often started masturbating in the lounge, admittedly shocking some of the other residents and staff. The thing is, you could not really call his behavior inappropriate as he was doing what felt nice to him. The problem was the location was completely inappropriate.”

There Are No Hard and Fast Rules to Respond to a Specific Situation.

- A person centered care approach is recommended.
- Approaches are different for each person
- Assessment of behavior, function, cognition is needed.
- Evaluations are needed.
- Involve the team, family, partner and physician.

How Should You Respond to Inappropriate Behavior

- Currently (2011) there are no medications specifically for sexual inappropriate behavior.

- *Use Non-pharmacological Approaches*

  Activity Therapy, Art, Music, Pet Therapy, Reminiscence, Drive in Car, Outside Walks, Sensory Rooms, Aroma Therapy, Reiki, Rocking Chairs, Mint or Charms Lollipop, etc.,

Behavior Log
Try to Determine Triggers for Behavior

Consider using a behavior log to document

- What activity was going on right before this incident occurred?
- What happened right before the behavior?
- What was the behavior?
- What action did staff take regarding the behavior?
- Was action / intervention effective?

How Should You Respond at the Time of a Sexual Nature which You Consider Inappropriate in Some Way?

- Remain Calm. Don't show shock or embarrassment.
- Be respectful to the resident and preserve dignity.
- Reassure other family or resident's present that patient means no harm.
- Staff should show no awareness that behavior is inappropriate or shocking.

- If in a common area lead resident away
- If touching you in a way you are uncomfortable, for example during ADL care in the bed: Step away from bed, state using a firm tone, “Mr. Smith, I am Sandra, your nursing Assistant. I am here to provide a sponge bath. Do not touch me there.” You may need to excuse yourself and come back later.
- Do not reprimand, scold or yell.

What Should You Consider After the Event?

1. What form does the behavior take?

- In what context?
- How frequently does it take place?
- Review resident's behavioral history.
- Consider speaking to family or partner to gain a greater understanding of their social and sexual history.

What Factors Contribute To This?

2. Could there be a social, environmental or psychological cause?

- Has there been a change in routine or environment?
- Is there a lack of privacy forcing them to express sexual behavior in overt fashion?
- Resident believes other person to be someone they know intimately?

- Resident misinterpreting the actions of the care worker? Watch your language for example; don’t say “I am here to get you up.”
- Have you checked to make sure no underlying medical conditions or medications contributing to behavior?
- Have you assessed the resident’s mental well being? Such as depressed, lonely, manic or seeking reassurance, comfort or touch.

- Seeking to take clothes off, have you assessed if clothes irritating, not fitting correctly, over dressed or under dressed?

Reflect On How You Define and Classify Inappropriate Behavior

3. How did you form your judgment and does this behavior offend your attitudes , cultural beliefs or values?

- Do you find the behavior inappropriate because you feel it would be judged so by other staff members, residents or family?

Consider What Risks are Involved?

4. Does resident pose a risk to others?

- Is he a risk to himself?
- Assess the awareness and understanding of resident's behavior.
- Continue ongoing assessments of the resident's mental capacity.

Also Consider Cultural Considerations When Conducting Assessments

- Language and need for interpreter
- Can They Read
- Immigrant Status
- Economical Status
- Perceptions of Institutions
- Perceptions of Disability
- Role of Family in the Decision Making

Take Care Of You

- If you have been the object of ones aggression or inappropriate behavior it is understandable if you are upset, angry or even emotional.
- Seek support and reassurance from support staff and colleagues.
- Report all behavior that may be inappropriate

Case Studies

- Read Case Studies Andrew and Jane's Story, Frank and Maggie's Story, George, Anne and Veronicas Story, Sinita and Dorothy Story, Jacks Story.

- What are your opinions concerning the case studies?

Review Case Studies

- Bills Story
- Paula and David's Story

Be Aware of Adverse Effects of Medications

- Medications may diminish sexual desire.
- Medications may begin new behavior and sexual aggression.

Other Reasons for Diminish Sexual Desires

- Feelings of being unattractive. Develop self esteem programs.
- Physical limitations.
- Attitudes of staff and family.
- Erectile Dysfunction.
- May view the partner as sick so no desire.
- Partner may be hyper sexual and this is a turns off well spouse.

Older People From The LGBT Community Lesbian, Gay, Bisexual and Transgender

- Not all older people are the same.

- In the future there will be more people who are LGBT living in your senior communities.

Remember, this generation (LGBT) has spent a lifetime keeping their private life, private.

Older people may be fearful of;

- Attitudes of Staff, Resident's, Volunteers, Family.
- Potential prejudice of staff and residents and families.
- They then may assume heterosexual behavior because they view this as detrimental to their wellbeing in a long term care setting.

Case Example for LGBT

- “There was one lady in the care home who did not have a partner but we could tell she preferred women to men. Sometimes the care staff did find her trying to touch other women which for some reason either provoked complete outrage or extreme amusement amongst the staff. Neither response was appropriate and it just served to remind me how much work we still needed to do on this issue.”

We Need To Be Accepting

- Support & acknowledge the LGBT patient need for intimacy
- Offer support and reassurance for patient and partner.
- Acknowledge and understand that family and staff may be embarrassed, ignorant, nervous and prejudiced against LBGT older community.

Train Train Train

- Provide equality training, cultural diversity training, LBGT & sensitivity training to staff & management and family.
- Review policies and procedures to ensure inclusive and open environment for full spectrum of sexualities.

Be richer for knowing more about people who are different than you!

Provide Information on Safe Sex

- Age is not a barrier to sexually transmitted diseases including HIV which leads to AIDs.
- Does the facility provide condoms? Should they?
- Provide advice, resources and support.
- Provide safe sex in-services to patients and staff.
- Good hygiene is imperative to avoid risk of infection.

How To Develop Good (Best) Practice and Policy on Dementia, Sexual Expression Behavior and Intimacy

- Encourage residents to cultivate friendships but monitor to ensure that this is the best interest for all involved.
- Promote opportunities for residents to spend time together if in the best interest of both parties.
- Provide opportunity for residents to touch or stroke such as pet therapy, soft stuffed animal, or fake fur.

- Promote a safe and secure environment in terms of safe sex.

Support and Training

- Provide ongoing training regarding dementia awareness, cultural diversity and sexuality.
- Provide ongoing strategies to workers on tips responding, awareness training, exploration of attitudes, cultural values and beliefs.
- Provide support staff to discuss concerns staff may have.
- Look at how management address the anxieties and embarrassment of the staff.

Policy and Practices

- Review your policies
- Do you have policies and procedures in place with regard to responding to the intimate and sexual needs of the residents with dementia?
- Create working definitions for;

  Sexual intimacy and sexual behavior

  Sexual behaviors requiring assessment

  Sexual behaviors of concern / risk

- See what other facilities or agencies have in place (Policies, Evaluation and Assessment Tools, Investigative protocol).
- Are you asking for information about sexual and social history?
- How do you record and monitor situations of a sexual or intimate nature?
- What are the values your company promotes?

Baby Boomers

"Make Love Not War"

- Baby Boomers are creating a second sexual revolution per AARP study of sexual practices of Americans 45 and older.
- Their attitudes towards sex and older adults will forever change the way people think about sex. (Pioneering Change)
- They believe that sexual dysfunction needs to be treated.

Baby Boomers

- They are not willing to exclude sexual needs as part of growing older.
- They feel sex is ageless.
- Women believe they are entitled to sexual pleasure and bring a whole new meaning to "Do It Yourself!" (Pioneering Change)

  Women felt regardless of availability of a partner, they identify self stimulation as an important part of sexual pleasure at any age.

Pioneering Change

"It is always proper not to make assumptions but examine the value systems of all involved parties and provide appropriate training so all staff members will approach residents' sexuality in a uniform manner."

(Pioneering Change)

Resource Handout

Thank you to the International Longevity Center-UK London in granting permission for the NCCDP to utilize this important document.

"The Last Taboo A Guide to Dementia, Sexuality, Intimacy and Sexual Behavior in Care Homes"

http://www.ilcuk.org.uk/index.jsp

Please see this web site to download the handout document. Free Download

National Council of Certified Dementia Practitioners: Links and Resources

- See our web site and Sexuality Resources, Assessment Resources, Capacity Resources
- At www.nccdp.org

Resources

"Considerations Regarding the Needs of Long Term Care Residents for Intimate Relationships and Sexual Activity" Free Download

The Center for Practical Bioethics

http://practicalbioethics.org/wp-content/uploads/2011/07/Intimacy_Guidelines_Aug2007.pdf

Resources

Kansas Department on Aging

Peak Nursing Home Initiative

Culture Change Education Modules

Free Download

“Pioneering Change

Sexuality in Nursing Homes Education Modules”

http://www.agingkansas.org/LongTermCare/PEAK/peak.htm#modules

Resources

Dementia Care Mapping- Free Download

http://www.bradford.ac.uk/health/dementia/DementiaCareMapping/

Dementia Care Mapping Book through Amazon

Resources

Delivery of The National Dementia Strategy

The Alzheimer's Society UK Recommends How To Implement the UK Strategy

"Information Needs of People With Dementia and Carers." Download Free Document http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=968

Assessment Resources

- Hartford Institute for Geriatric Nursing Try This Series. Free download assessments tools
- http://hartfordign.org/practice/try_this/

Resources

Freedom of Sexual Expression: Dementia and Resident Rights in Long Term Care Facilities Video. Terra Nova Catalogue
www.terranova.org

Resources

- Dementia Care Plan Dictionary Book can be ordered through www.activitytherapy.com

- Article: Sexually Transmitted Diseases in the Elderly: What You Need To Know

  Sexual History Form for Elders. Free Download

  http://libres.uncg.edu/ir/uncg/f/S_Letvak_Sexually_1996.pdf

Resources

Proactive Sexual Health History Article with Sexual History Form

American Family Physician Web site.

Free Download

http://www.aafp.org/afp/2002/1101/p1705.html

Resources

Assessment of Older Adults with Diminished Capacity

American Bar Association

Free download 186 pages

See consent pages for Sexual Consent pg 68-71

http://www.apa.org/pi/aging/programs/assessment/capacity-psychologist-handbook.pdf

Resources

- Mental Capacity Assessment Tool http://www.face.eu.com/our-products/assessment-tools/mental-capacity-assessment-toolset

Recommended Reading

Sexuality and Long Term Care: Understanding and Supporting the Needs of Older Adults

By Gayle Doll Published 2011

Book Available through www.activitytherapy.com

Behavior Log

Growing Options

ABC (Antecedent, Behavior, Consequence)

Chart Form

http://www.scribd.com/doc/13030287/Behavior-Chart-FormGrowing-Options

Aged Care

Behavior Chart see page 11

http://www.accreditation.org.au/site/uploads/Dementia-identifying.pdf

Resources

Mental Competence and Capacity Web Site

http://www.competence-capacity.com

Judicial Determination of Capacity of Older Adults in Guardianship Proceedings

A Handbook for Judges. Free Download

http://www.apa.org/pi/aging/resources/guides/judges-diminished.pdf

Intimacy, Sexuality and Sexual Behavior in Dementia Free Download

http://www.fhs.mcmaster.ca/mcah/cgec/toolkit.pdf

Sexuality and the Alzheimer's Patient. Manual. Small fee from Duke University. See order form.

http://www.geri.duke.edu/service/dfsp/DFSPpublicationlist020808.pdf

- Self Esteem in the Elderly Book
  www.activitytherapy.com
- Dementia Care Plan Dictionary
  www.activitytherapy.com

Thank You To
Center for Practical Bioethics

Tarris Rosell, PhD, Dmin

Rosemary Flanigan Chair

Center for Practical Bioethics

Professor of Pastoral Theology--Ethics & Ministry Praxis

Central Baptist Theological Seminary

Clinical Associate Professor, History & Philosophy of Medicine

University of Kansas Medical Center, School of Medicine

Thank You To
Center for Practical Bioethics

Michael E. Salacz, MD

Medical Director

Saint Luke's Brain Tumor Center

Neuro-oncology Clinic