

CHANGING DYNAMICS: STRENGTHENING FAMILY RELATIONSHIPS AS PEOPLE AGE

MENTAL HEALTH ISSUES IN LONG-TERM CARE

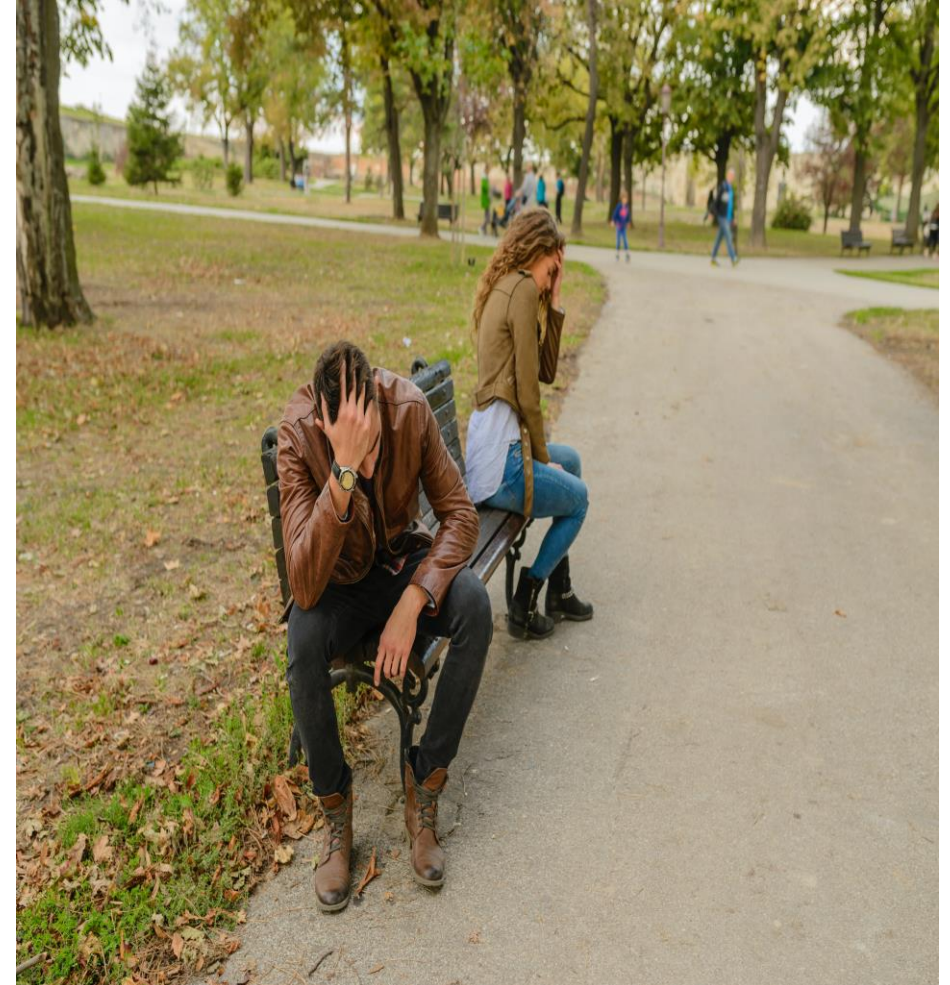
CHRISTOPHER SPARKS, LISW

I Have No Financial Conflicts Of Interest To Disclose

Getting Acquainted

Couples face a myriad of challenges:

- Poor communication,
- Inattention to the other's needs,
- Lack of intimacy,
- Disagreements about parenting,
- Financial stress,
- Substance Abuse,
- Infidelity...



Practice Trends in Couple's Therapy



Couple's and marriage counseling at the CMHC in Waterloo, practice trends.

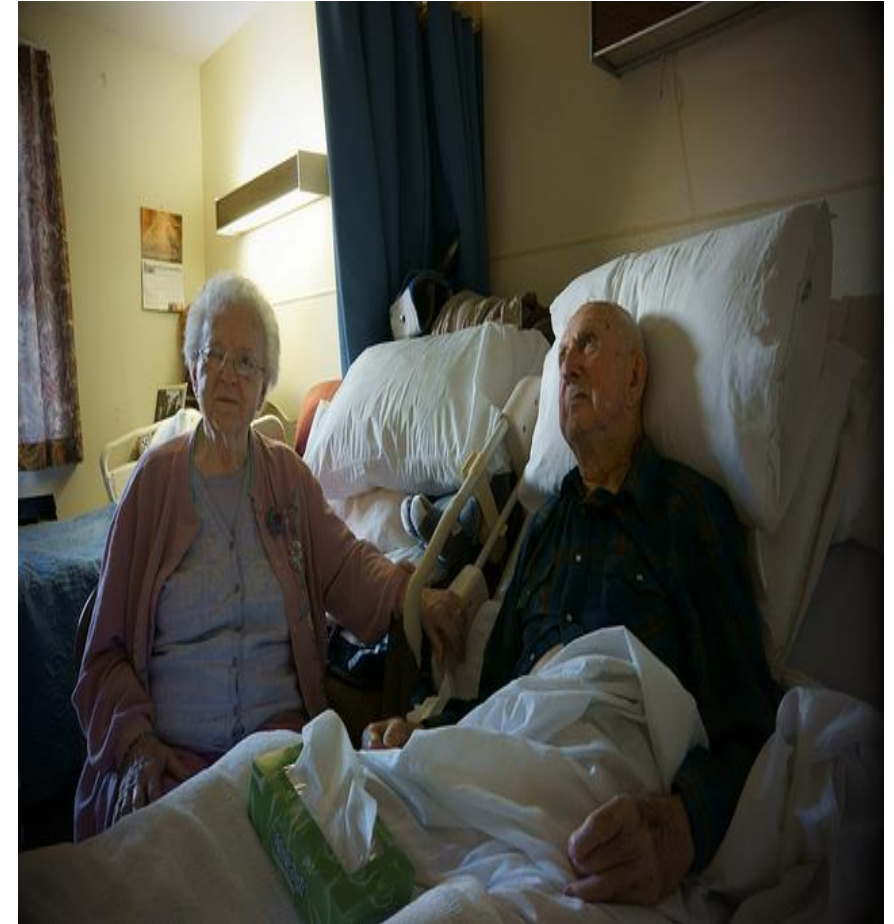
- Couples where one or both had a serious mental health diagnosis.
- Same sex couples, trans couples, adult parent/child, and
- Older couples married over thirty or even forty or more years.

Challenges Facing Aging Couples

The American Community Survey, data from the US Census:

- Considers someone to have a disability if they reported vision, hearing, cognitive, ambulatory, self-care or independent living difficulty.
- Annually, during the 2015-2019 period, about 18.2 million older people, or about 36.0% of people ages 65 and older, reported at least one disability.
- Disability can create caregiving needs.

US Census Bureau



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Caregiving in America

Caregiving: help with activities of daily living, paying bills, shopping, or transportation. It also includes the provision of emotional support and managing chronic disease or disability.

- In the US, middle-aged children and older adults provide a substantial portion of care.
- Caregiving demands can impact a person's ability to work, maintain essential social connections, and can even affect their physical and mental health.



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Caregiving in Iowa

- In Iowa 16.8% of adults age 45 or older reported being a caregiver to friend or family member.
- Of those people, 10.5% of them reported struggling emotionally with stress and depression.
- Over 37% of caregivers in Iowa reported having serious health problems themselves, like heart disease, cancer, COPD, etc.
- In Iowa nearly 18% of adults age forty-five or older expect to be caregivers in the next two years.



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Helping Couples Navigate Long-Term Care



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The decision for a loved one to go into LTC elicits a myriad of emotions:

- stress, guilt,
 - anger, anxiety,
 - depression,
 - and continuing burden
- Spouse roles shift from provision of hands-on care to that of visiting, monitoring care, and serving as an advocate for their institutionalized relative.

Challenges to Successful LTC Placement

1. Coming to grips with group services. Activities, meals, etc. are geared to a common set of interests and abilities.
2. Relinquishing control.
3. Staffing instability.
4. Confusion about family participation/roles.
5. Surrendering terminal life goals.



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Challenges following couples into LTC

Complicating Factors:

- Communication
- Time together and intimacy,
- Sexuality,
- Role changes,
- Surrendering terminal life goals,
- Any significant and unaddressed relationship problems (abuse, substance abuse, infidelity, neglect, etc.).



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Couple's Transitioning to LTC

- Trust is an overarching issue for families placing a loved one in LTC setting.
- Trust can be built over time.
- Families have to get to know staff.
- Scheduling and workforce challenges make this harder.
- Families want an assurance that staff are capable *and* decent human beings.
- Families struggle to understand the regulatory and organizational demands of the facility.



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Couple's Transitioning to LTC, continued



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- Threading the needle on family involvement:
- Personal care and ADL assistance,
 - Activities outside the facility,
 - Managing finances,
 - Providing social support and companionship,
 - Monitoring care and advocating interests of their loved one,
 - Providing important and helpful background knowledge on their loved one.

Supporting Couples after LTC Placement

After placement loved ones often experience ambivalence.

- They feel relief after the stress of providing home care for their partner,
- But they feel responsible for their partner's having to go into a nursing home
- Losing control, it can be difficult for loved ones to let go,
- Conflicts over care expectations.
- Family can attempt to control care staff and show a strong desire to be involved in their loved one's care.



Supporting Couples after LTC Placement



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- Success is more likely if families receive an orientation, tour, and meet key staff. And if the facility:
- Defines pathways for families to communicate with staff and leadership.
 - Builds trust: studies suggest it's critical for spouse and resident satisfaction.
 - Upholds clear standards.
 - Responds to and resolve problems.

Supporting Couples after LTC Placement

Redefining the caregiver role:

- Help families transition from hands-on care provision to a focus on spending time and offering emotional support.
- Families negotiate changes in roles with staff, which requires some finesse and confidence on the part of staff.
- These changes can be very challenging for families.



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Supporting Couples after LTC Placement

Care Expectations: the dilemma over care standards.

- Facility versus family care.
- Diligence, responsiveness, and reasonable expectations are critical.
- “Little things” can be quite important such as personal appearance, missing clothing, food preferences not being honored, or not showing interest or investment.
- Families often are concerned about access to medical treatment and medical staff competence.



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Supporting Couples after LTC Placement

- *Communication*: getting needed information and communicating concerns.
- *Psychosocial Factors*: Boredom, loneliness, and guilt.
- *Dealing with the deterioration of the loved one*: challenging for families to witness physical and cognitive decline.
- *Organizational Barriers*: staffing challenges including understaffing and changing faces. Staff who are unfriendly. Physical conditions not meeting expectations.



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Strengthening Couple and Family Relationships

- Support Role Transition from Caregiver to Supportive Spouse.
- Visit Structure and Activities: How do people spend time together?
- Allow Space and Time for Intimacy: Closeness, comfort, shared feelings, shared interests, friendship.



Supporting Couples after LTC Placement, bigger problems...

1. Improving Communication.
2. Resolving long-standing conflicts.
3. Rediscovering time together and intimacy.
4. Renegotiating the relationship agreement.
5. Finding the next chapter in their story.
6. Managing extended family problems.



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Strengthening Couple and Family Relationships

Relationship attributes that strengthen couples:

- **Flexibility:** ability to adapt to the challenges of long-term care placement, separation, and disruption. Disruptive transitions require a willingness to change, balanced by efforts to stabilize routines.
- **Connectedness:** Couples that balance needs for intimacy and mutual support with respect for separate pursuits and individual differences.
- **Social and Economic Resources:** Couples with good and reliable familial and social support and adequate financial resources function better after long term care placement.

(John Rolland's Family System Illness Model, adapted)

Strengthening Couple and Family Relationships



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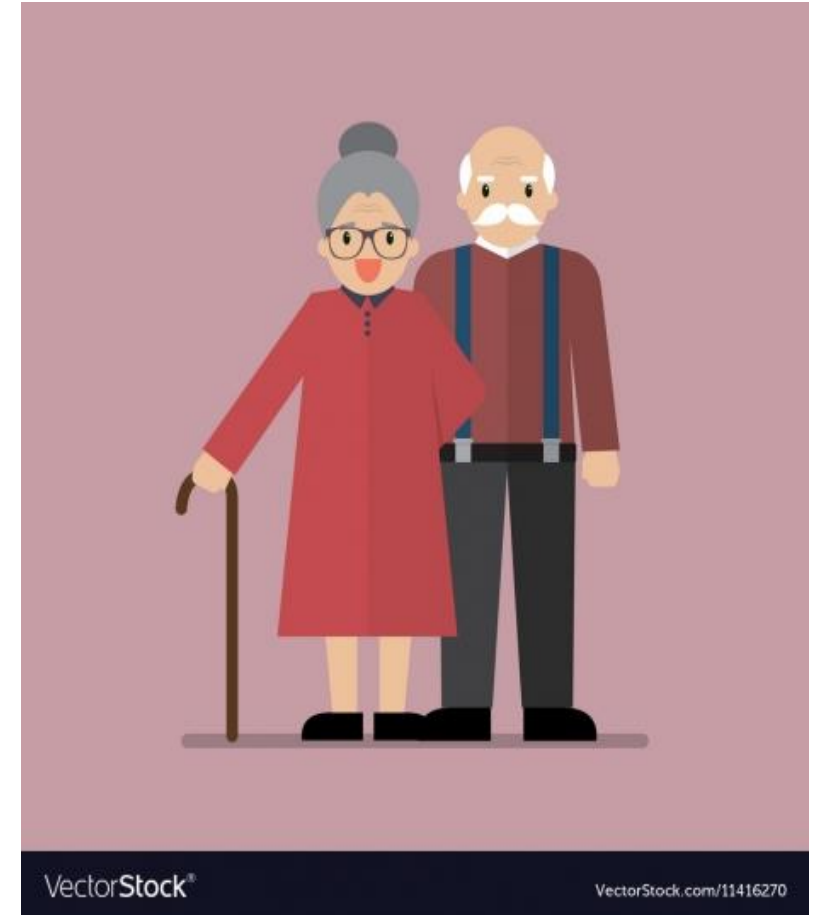
Communication is essential for couples in transition:

- **Clarity:** clear and consistent messages in word and action. Clarify any confusing information. Be truthful.
- **Emotional Expression:** the couple (and family) should share emotional struggles honestly (e.g., fear, anger, disappointment, grief, etc.).
- Couples need to **share affirmative feelings;** joy and excitement, love, appreciation, gratitude, humor, fun, etc.
- **Collaborative Problem Solving:** couples need to solve problems together, share decision making, focus on goals, work to be proactive, and prepare for future challenges.

(John Rolland's Family System Illness Model, adapted)

In Closing:

- Under the best of conditions, couples and families face trials and tension.
- Physical and cognitive decline and family members becoming caregivers puts stress on families.
- The decision to seek long-term care for a loved one is difficult and results in a complex mix of emotions.
- Helping the couple adapt to long-term care placement and continue to function as a couple results in dramatically increased satisfaction. It's largely uncharted territory.



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