Honoring Choice in Challenging Situations

Dane County Dementia Support Team (DST)

GOALS:

- Brief history of how the DST was developed
- Purpose of DST
- Overview of team members / roles
- Case examples
- What we have learned?

History:

- Team was developed in 2009 through a partnership between Dane County Human Services, Mendota Mental Health Institute – Geriatric Treatment Unit (GTU), South Madison Coalition of the Elderly and the Alzheimer's and Dementia Alliance of Wisconsin
- Shared concern that persons with Dementia were getting "stuck" in Mendota Mental Health Institute due to a lack of appropriate resources to support them back in the community

History:

- Extended stays in the GTU are difficult for persons with dementia – the setting was created to serve persons with mental health issues
- GTU staff do not have the time, money or resources to build the type of service plans they would like to be able to create for persons leaving the GTU would need to ensure their health and safety back in the community
- Limited provider options / services to support high level of behavioral needs in a community setting
- High financial burden to Dane County - $1000 per day to provide care

The Dementia Support Team:

- Goal:
  - To assist Dane County residents with a diagnosis of dementia / neurocognitive disorder who have been admitted to the GTU to return to the community as soon as they are able to do so by building an individualized discharge plan which promotes health, safety, quality of life and reduces the risk of a return to the GTU or other hospital setting
  - To prevent GTU admissions for adults diagnosed with Dementia / neurocognitive disorder who receive Community Options Program (COP-W) Funding and are at risk of being admitted to the GTU

The Dementia Support Team

- Goal:
  - Gathering information to understand the circumstances surrounding the admission / escalation of expressions
  - Identifying the specific type of dementia a person may have
  - Looking at medications
  - Assessing for strengths, personal preferences (Life Story)
  - Developing a person centered care plan
  - Providing training / support to caregivers, families, providers based on the care plan / Life Story with the goal of helping everyone know the best practice approaches to addressing a persons needs / preferences in a way that may minimize the expression of a behavior (aka communication!)
  - Organizing provider assessments @ the GTU, as applicable
  - Identifying /creating community placement options

The Dementia Support Team:

- Who Are the Team Members ?
  - The person with dementia
    - His / Her family, guardian, informal supports, caregivers, etc
  - GTU Staff:
    - psychiatrist, social workers, nurses, therapists
  - South Madison Coalition of the Elderly:
    - Jodie Castaneda, Social Work Case Manager
    - Molly Schroeder, Social Work Case Manager
    - Lisa Krakow, RN Case Manager
  - Alzheimer's and Dementia Alliance :
    - Dr. Kim Peterson, MD
    - Joy Schmidt, Community Education Specialist
  - Community Providers / Partners:
    - CBRFs, AFHs, Supported Living Agencies
    - Home Care Providers
    - DME, transportation, ADC, etc

South Madison Coalition of the Elderly

Jodie Castaneda, Social Work Case Manager

Case Manager Role:

- South Madison Coalition of the Elderly (SMCE) contracts with Dane County Human Services to provide discharge planning and, if needed, on going case management through COP-W
- Currently two social work case managers and one RN case manager are part of this specialized team
- Additional supports provided by SMCE:
  - Consultation with other COP-W case managers in Dane County to help problem solve and minimize risk of potential admissions to GTU
  - Assess for functional and financial eligibility for COP-W as a way to support a person returning to the community

Case Manager Role:

- Initial Referral Process:
  - Notification from DCHS Community Services Manager when someone is admitted to the GTU with a diagnosis of dementia
  - Information gathering begins:
    - Clinical, financial, legal status
    - Sense of medical / cognitive stability – is it possible? What is needed?
  - Challenges at Information gathering phase:
    - Getting an accurate history of what led to placement
    - Impact that legal status has on timelines
    - Families / guardians who have been through a very stressful period and having to “tell their story” again

Case Manager Role:

- Goals of Assessment / Information Gathering:
  - Identifying placement options based on feedback from professionals, family, guardian and what is available
  - Coordinating services / training needed to help increase odds of a successful placement back into the community
  - As needed, may have to advocate for additional time if appropriate options are not available – even if the person may be cognitively / medically ready to leave the GTU
    - Advocate for choice
    - Involve APS and/or LTC Ombudsman to protect rights
    - Trying to ensure health and safety while honoring choice with what may be limited options – a very difficult balance
  - Communication, communication, communication all along the way

Case Example:

- Service / Discharge Coordination for Henry H.
  - CBRF placement needed due to care needs
  - Henry was connected to another social service agency prior to admission to the GTU
  - Worked closely with other agency to learn history and preferences of Henry as they have understood them to be
  - Henry presented some specialized health issues that could have been a barrier to placement
  - Keys Things Needed for Placement:
    - Education of staff about Henry's specialized medical needs
    - Additional 1:1 staffing due to Henry's constant need to move
    - Customized clothing to protect him from falls, bumping into things
    - Staff learned about what Henry has loved in his life – ie Ellen Degeneres, walking, etc.

Case Example:

- How was Choice Honored?
  - Decision as to whether or not to pursue Hospice
  - Whether or not to continue to let Henry be up walking as much as he was even though he was falling a lot
  - Should Henry be supported in going out for walks / outings in the community? What if he didn't want to come back into the CBRF?

Case Example:

- What is most important is that Henry was able to live out his remaining days in a homelike setting where his partner felt he was loved and accepted for who he was. His partner was able to be just that again – his partner.

- Henry died peacefully at home with the love of those who cared for him surrounding him.

Alzheimer's and Dementia Alliance of Wisconsin

Joy Schmidt, Community Education Trainer

Labels

- Anxious / moody
- Withdrawn in groups
- Wanders - at times
- Swears /lost filters
- Procrastinates
- Agitated- at times
- Intrusive – at times
- Doesn’t follow social norms
- Doesn’t follow rules

It could be her.

Or….
it could
be
Her!

Words have power!

- Re-think the labels we assign to people.
- They follow the person.
- Remember that some day this might be you or someone you love.
- Find positive ways to describe behavior and look for our part in causing the behavior.
- Look at what the person is trying to communicate with this behavior and try to meet that need.

ADAW's role in the Dementia Support Team

Gathering Life Story

- From the chart
- From family and friends
  - Unique perspectives
- From the person with dementia
  - What is their reality?

Always focus on the positive!!

Communicating the information…

- Written document for the chart
  - Thorough, includes details about likes and dislikes and suggestions specific to the person.
- Life story book for the client and direct care staff
  - Laminated book with details about their life.
  - Can be used as a tool to help with interaction.
  - Can be a comfort for the client as they are losing their life story. (May not work for everyone.)

What should we know about the past?

- As much as possible!
- Birthplace, childhood memories
- Family and work life
- What do they value
- How have they managed stress
- What was their personality like… ex.: leader, follower, anxious, laid back.
- Upsetting events in their lifetime
- Music they enjoyed when they were young

What should we know about the present?

- What is their routine
- What do they enjoy
- What do they like, what don't they like
- What makes them feel happy, calm
- What makes them upset or afraid
- What kind of music do they enjoy
- What is their reality… where are they now

“Dee”

Deidre

Smith

Dee was born in Green Bay, Wisconsin

She was the 11th child out of 12 children. Her maiden name was Daniels.

Education

- She completed 10th
- She met her husband and had her first child while still in school

Her Siblings

1. Alice
2. Edmund
3. Dan
4. Hank
5. Eunice
6. Otto
7. Harold
8. Lisa
9. Renee
10. Betty
11. (Jan)
12. Tom

Family

- Dee was married twice
- She married Bob in 1967. They were married 33 years and were very happy. He treated her sons as his own.
- She had 3 boys with her first husband
  - **Sam, Scott, Sid**
- She had one daughter with Bob
  - **Mary**

Pets

- She had a dog and cats when her kids were young

These are her primary visitors:

- Her son Sam
- Daughter-in-law Julie
- Grandchildren
  - Erin and Ethan

Work

- She was a hard worker
- She stayed home with her kids until the mid 70's
- She worked as a nurse aide in a nursing home

She had a few retail jobs…

- She also worked at:
  - Joann Fabrics
  - Shopko
  - Dry cleaning

Other Work

- She and her husband ran a business from home. They sold press printing parts.

Her husband taught her to play guitar

- They would play together for their friends in the back yard
- They liked country and western music

She had a lot of friends

- They would play croquet
- Play music
- And play games
  - Rummy, UNO, 31 and video games (PacMan)

She likes being outside

- She had flower beds
- Potted flowers
- Bird feeders

She also liked…

- Swimming
- Snowmobiling
- Fishing

Escape

- She liked to walk in the woods
- She liked watching the bears at the dump
- She would say… “Let’s go for a ride and get lost.” She liked to explore.

Religion

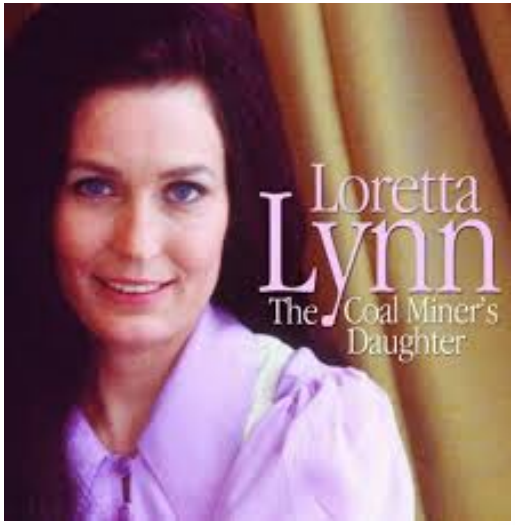
- Church services comfort her
- She attended protestant churches
- She enjoys the hymns

Television

- She likes old movies and TV shows
- Sometimes it scares or upsets her now

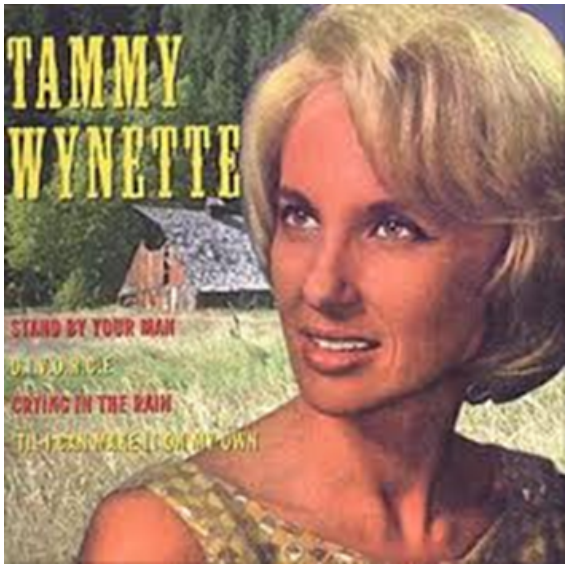
Music

- She likes country and western most
- But she also likes some rock & roll and most music
- Her favorite artists:
  - Patsy Kline
  - Loretta Lynn



Other favorites…

- Johnny Cash
- Tammy Wynette
- George Jones



Vacations

- She liked to go to her grandmothers cottage on Gilke Lake in Northern Wisconsin

Branson, Missouri

- She and her husband visited Branson a number of times
- They liked the music
- They would go with friends.
- She has pictures of herself with Jim Stafford and Loretta Lynn

Meals

- Breakfast -- just juice or milk
- Lunch and dinner are her primary meals and she's not picky about food
- Favorites:
  - Ice cream, chicken and black olives

Pain

- Sometimes she has pain in her left hip
- She has some arthritis
- Abdominal pain and constipation occurs often for her

Vision / hearing

- She had good vision but was seeing double at one time
- She did use reading glasses at one time
- She is able to hear and does not wear hearing aides

Sometimes she likes to dance…

ADAW's role in education….

- Evaluate environment and staff's approach
- Observe and work directly with client to find what works and look for trends when it doesn't
- Gives outside perspective
- Find strengths of client and validate staff for best practice care
- Personalize the plan of care
- In-service education specific to the individual but can also be used more generally

Case example…

Jan was about to get a 30 day notice. She had been living in this memory care facility for approximately one month but the staff found her very difficult and didn't believe they could care for her. She was going into other residents rooms and slamming the doors. She believed that staff was going to kill her and the other residents. She was resistant to care and continued to pack her clothes daily as she was going home. The facility staff believed that her behavior was indicative of a psychiatric condition rather than dementia because it could not be "paternized". They also believed that because she had no social supports that this must indicate a personality disorder.

We came in and got to know Jan. She had no previous history of a psychiatric condition. She had been living with her husband and providing care for him until he died. He had physical issues and she was having memory issues. They didn't have children. They lived out in the country and had a beautiful home with many gardens. She was a hard worker but they lived a quiet life. She had been deaf in one ear since birth. The staff was having difficulty communicating with Jan. She was fearful and angry.

Results:

1. Transitions take time. It takes people with dementia longer to adjust to a new environment. She needed to feel safe and to have activity that kept her stimulated. She was a hard worker.
2. We found out Jan could read! This was such a strength and it allowed the staff to communicate with Jan. They hadn't thought to try this. Think about "abilities" rather than disabilities.
3. Jan read faces. She learned this from childhood when she couldn't hear. She was very in tune to facial expressions of the staff and other residents. This could trigger anxiety for her. Being aware of this helped.
4. They were blaming Jan for her lack of social supports. It wouldn't take long to be left without supports if you don't have children and if you are someone who enjoys solitude. It doesn't mean that she has a psychiatric condition. Dementia can cause people who have no history of psychiatric issues to show delusional behavior.
5. She told us that she slammed doors because that's how she locked them.
6. She was easy to re-direct. If she talked about something upsetting, as long as the staff changed the word or the subject, she moved on. She loved talking about flowers.
7. Jan was able to remain and the staff said our intervention was a "blessing."

When Alzheimer's disease touches your life, we're here to help.

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What Have We Learned?

- This is an ever increasing need. Efforts are needed at a systematic level to learn how to better redirect and prevent admissions into a GTU type setting. We recognize our model is small and specialized – how can be grown to achieve the same goals? We are working on this…
- Consider "step down" options from an institution to allow additional time for planning / learning before a final move back to the community
- Stay focused on the goal of supporting the individual - let go of a sense of territories / control. If everyone is committed to the same outcome it may not always matter how or who brings us there – just that we get there with our individual leading the way as much as possible

What Have We Learned?

- The importance of a thorough neurocognitive assessment to get an accurate diagnosis of the type of dementia. Helen E. F. Case has led to an increase in Chap 55s being converted to Chap 51 because dementia is not viewed as a treatable mental illness meaning discharges need to legally occur within 30 days of the probable cause hearing. How can things be changed at a legislative level to accommodate the needs of persons with dementia?
- Approach, approach, approach! How we choose to approach and respond to difficult situations will directly impact the outcome of the situation – we cannot expect the person to change what they are doing. It is our job to adjust to preserve their dignity and respect.

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