

MANAGING & CARING for
him /her on the ROAD with:
DEMENTIA



CONNECT TO CARE

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OUTCOMES - Learn more about:

- ❖ **Hope**/help for people (and fam) with Dementia?
 - Attitude (GP & Fam) determines Altitude – left to die vs loved & stimulated.
- ❖ **Understand** the roadmap – how to walk this challenging road....
 - Types of Dementia & Brain Failure /Signs, symptoms -"Text book case" /Stage of illness.
- ❖ **Learn** to use **tools** /develop **skills** to cope!
 - Medical & Lifestyle tips /Communication /Counselling: Acquire patience /Educate to *perform selfcare*
- ❖ **If I am diagnosed today**I'll react with I'll ask take care of me when I can no longer do it for myself & preserve my dignity...



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DAUNTING TASK?

- **Reflections of who we are:**

TOM HUSSEY

Feelings /Thoughts ??

❖ **SAFETY CONCERNS / HARM & DANGER = RISKS**

- Self neglect...** not taking medicine, not eating, poor hygiene
- Wandering** – getting lost....
- Risk of Falls** – supervision, caregiver, Biokinetics exercises.
- Self Harm** – suicide risk /incorrect medication /fire.
- Aggression** (verbal or physical) and harming others

AIM: Quality of life: Patient, Fam & Caregivers

CARE PLAN = NEED's based:

- ❖ **Structure & Daily Routine with stimulation activities & rest**
- ❖ **Premorbid personality & hobbies, likes & dislikes**
- ❖ **Prevent Social Isolation (causes & worsens dementia)**
- ❖ **Avoid major changes in surroundings**
- ❖ **Create environment that limits noise, glare, insecure space and /or too much background distraction, including TV.**
- ❖ **Triggers & ABC chart – observation of causes of challenging behaviour (antecedent [trigger], behaviour, consequences)**

❖ **PHYSICAL HEALTH:**

- Healthy **Diet** – Mediterranean /Adequate fluid intake
- Adequate **Sleep** (Physically tired, Milo, calm night routine & light on)
- Physical **exercise** – brain requires oxygen (20 min walking & stretching) /Walking Aids
- **Check** for pain, hunger, thirst, constipation, full bladder, fatigue, infections & skin irritation as well as comfortable room temperature.
- **Regular physical check up** – B/P, Vit B, Vit D, Thyroid, Liver, Kidneys
- Management of **Chronic Disease** e.g. Diabetes
- Fitting & working **hearing aid, dentures** fit properly

❖ MENTAL HEALTH

- Premorbid Personality will dictate behaviour..... Grandma has always been a
 - Chief cause of behavioural symptoms is **progressive deterioration of brain cells.**
 - Presentation of irritability depression & anxiety **in the early stages** are common.
 - **Psychological difficulties** – depression, irritability, anxiety & fear (sense that something is wrong but do not know what), loss & grief; anniversary reactions **NB**
- Role of Specialised Therapist** (Psychologist, S/W, OT, Nurse)
- **Assist in managing** the fear & fatigue of trying to make sense of an increasingly confusing world.
- Diagnosis and stage of disease: Sensory stimulation vs basic or palliative care.

❖ **COMMUNICATION - Guidelines (With Courtesy from ASA):**

- ✓ Recognizing : person is not just "**acting mean or cantankerous," but is having further symptoms of the disease.... Calls for patience....** – NOT EASY! Repetitive Statements are challenging.
- ✓ **Eye contact**, able to see you. Stand /Sit in front of person, close enough to see **lips move & see movements of hands.**
- ✓ Use of **voice & body language** Speak slowly, quietly, use calm voice. Never shout or raise voice: results in anxiety & not hearing what is being said.
- ✓ **Appropriate touch; use their name** so person knows they are being spoken to. Helps keeping attention & helps them remember who they are.
- ✓ **Holding a person's hand** or sitting with **arm around her/him** shows care - respect choices.

❖ **COMMUNICATION – Guidelines (cont)**

- ✓ **Short sentences** - person can remember what they hear; questions **one at a time**, getting answer to first question before asking another.
- ✓ **Repeat**, a few times if needed and/or speak more slowly & clearly or change words being used.
- ✓ **Never use baby talk** or speak to the person as if s/he's a child.
- ✓ **Avoid being confrontational /arguing about facts.** E.g. a wish to go visit a late parent, don't point out that the parent is dead. Instead, say, "Your mother is a wonderful person. I would like to see her too." "White lies are acceptable"

❖ **COMMUNICATION – Guidelines (cont 2)**

- ✓ Use **Memory aids, writing instructions** –e.g. flash cards.
- ✓ **“Tolerate, anticipate, don’t agitate”** – e.g. Fear of water. Redirect the person's attention **distract** Try to remain flexible, patient & supportive by **responding to emotion, not the behaviour.**
- ✓ Listen carefully, do not pretend to understand. Guess what they are trying to say or are feeling by **using what you know about them.....** and **ask if you are right.** Encourage use of body movements to help you understand.
- ✓ Can ask them to repeat what was said but **do not ask to repeat it more than three times.** Rather, **ask them to show you** what they mean, if they can.
- ✓ Sadness, tearful, anxiety – require understanding & **encouragement to express reasons.**
- ✓ **Patience and more patience**

Management Tips:

❖ **AGGRESSIVE BEHAVIOUR**

- Communication - calm, soft spoken, eye contact, take control, reassure.
- Sensory control (use weighted sensory blankets, teddy bear, calming sensory room, soothing music)
- Medication --- prescribed by a medical practitioner with knowledge, experience.
- Restraint – only if permission from fam in writing, on Drs orders.

❖ **PSYCHOLOGICAL HEALTH of FAM MEMBERS** (family dynamics)

- ✓ Guilt feelings, depression, loss and grieving
- ✓ Denial, disagreement, financial constraints
- ✓ Respite Care
- ✓ Decision for care at home vs placement in a facility
- ✓ Support Groups

❖ CARE INTERVENTIONS where MEDICATION is LIFE SAVING...

- Can help & is often imperative..... Heart, Asthma, HT meds but “**shopping lists**” are dangerous.
- As per the **knowledgeable, ethical and experienced Drs’** prescription.
- Right to **understand potential benefits & risks** before making treatment decisions.
- **Start low dose of a single drug** & monitor closely for side effects. S/E can be serious, occasionally even worsen symptoms.
- **Do not stop /start any medication** because of S/E or ineffectiveness **without Drs knowledge** – record & report and **work with your chosen doctor**.
- **Dosage changes must be discussed** with & never done without a careful evaluation by a healthcare professional. Right to obtain a **2nd or 3rd opinion**.
- **Never share medication....**

❖ **MEDICATION (cont)**

- **Target specific symptom:** effective treatment of 1 core symptom may help relieve other symptoms. E.g. some antidepressants may help sleep.
- Paper from American Geriatrics Society, 2015 - **Beers Criteria**. Lists potentially inappropriate medications to be avoided in older adults, including those who are living with dementia.
- E.g. Older generation anti-depressants - Amitriptyline, Anti-psychotics - Risperdal /Risperidone as research has shown these drugs to be associated with an increased risk of stroke /death in older adults with dementia.
- **Appropriate use of Anti-psychotic medication** for Behavioral symptoms due to mania or psychosis, danger to the person or others, person experiencing inconsolable or persistent distress, a significant decline in function or substantial difficulty receiving needed care.
- Use of **seizure medication/mood stabilizer**.

CONCLUSION

This is a ***tough journey***.... complex, painful - learn & grow; search for & use available information and support which will make your own life more meaningful...

I wont necessarily remember what you did for me but will remember how you made me feel

Listen -
when I ask you to listen to me
and you start giving me advice
you have not done what I asked.

When I ask you to listen to me
and you begin to tell me why I shouldn't feel that way,
you are trampling on my feelings.

When I ask you to listen to me
and you feel you have to do something to solve my problem
and you have failed me, strange as that may seem.

Listen! All I asked was that you to listen, not talk or do - just hear me
Advice is cheap: 10 cents will get you both Dear Abby and Billy Graham
in the same newspaper.

And I can do for myself: I am not helpless
Maybe discouraged and faltering: I am not helpless
When you do something for me that I can and need to do for myself,
you contribute to my fear and weakness

But, when you accept as a simple fact that I do feel what I feel
No matter how irrational, then I can quit trying to convince you and
can get about the business of understanding what's behind
my irrational feeling
And when that's clear, the answers are obvious and I don't
need advice
irrational feelings make sense, when we understand what is behind them.

Perhaps that is why Prayer works, sometimes, for some people, cause God is mute
and does not give any advice or try to fix things
"They" just listen and let you work it out yourself.

So please listen and just hear me. And, if you want to talk, wait a minute for your turn:
and I will listen