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Tips for Managing Patients with Progressive Dementia in the Community: focus on responsive behaviours

Dr. Jo-Anne Clarke and Breanne Chohan OT Reg. (Ont.)

Disclosure of Affiliations, Financial Support, and Mitigating Bias

Speaker Name: **Dr. Jo-Anne Clarke & Breanne Chohan OT Reg. (Ont.)**

Affiliations:

- We have no relationships with for-profit or not-for-profit organizations.

Financial Support:

- This session/program has received an educational grant from NOSM

Mitigating Potential Bias:

- None

Session Evaluation and Outcome Assessment

These short forms serve important functions!

- For **speakers**: Your responses help them understand their strengths and weaknesses, participant learning needs, and teaching outcomes
- For **the CEPD office**:
  - To plan future programs
  - For quality assurance and improvement
  - To demonstrate compliance with national accreditation requirements
- For **YOU**: Reflecting on what you've learned and how you plan to apply it can help you enact change as you return to your professional duties

<u>Please take 3-5 minutes to fill the evaluation form out. Thank you!</u>

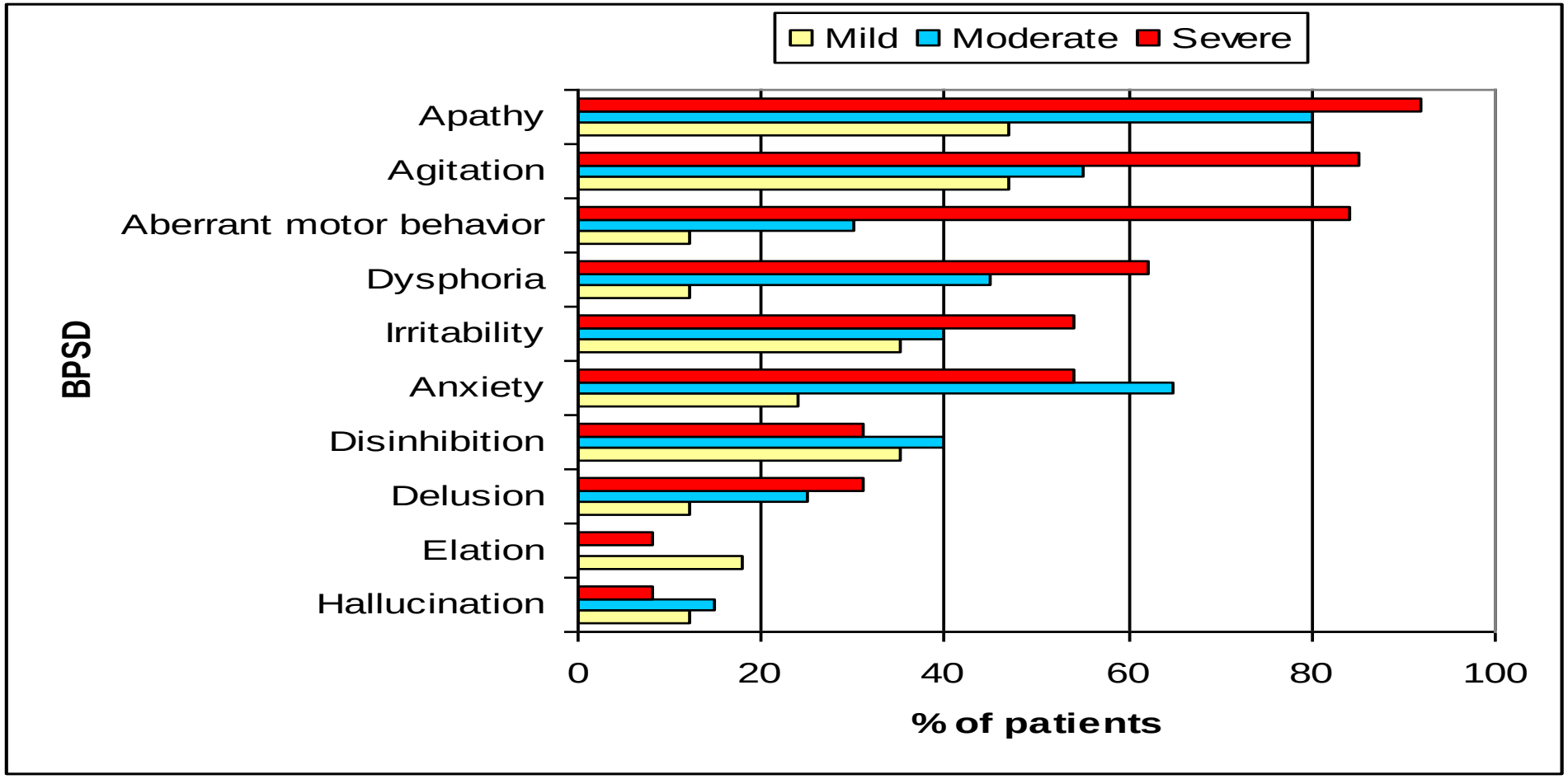
Learning Objectives

- Explain how to manage responsive behaviours in patients with dementia
- Describe ways to make the home environment safer for a patient with dementia

Part 1 – Managing Responsive Behaviours in Patients with Dementia

Dr. Jo-Anne Clarke

Behavioural and Psychological Symptoms of Dementia (BPSD)



Adapted from Mega MS et al., *Neurology,* 1996.

Managing Responsive Behaviours

- Language matters - be precise
- Responsive Behaviour
  - Wandering, crying, anxiety, agitation, aggression, calling out, exit seeking, hoarding, rummaging…
  - The behaviour is in response to something
- All behaviour has meaning
  - Instead of focus on the stress to us, to staff: ask, “what has made them upset” (Replace “agitate” with “upset”)
- Can also use “expressive behaviours” – what are they trying to communicate? To express?

What could they be saying

- I’m in pain
- I’m hungry
- It’s too noisy in here
- I’m lost
- I don’t recognize anyone / anything familiar
- I can’t find the toilet (I don’t remember toilets)
- I’m too foggy on all these medications
- I’m bored
- I don’t feel safe
- I need help
- I’m uncomfortable with what you are doing
- Don’t call me “dear” (avoid elderspeak)
- I can’t hear/ see what is happening

Responsive Behaviours for which medications (antipsychotics) will NOT work

- Calling out, repetitive questions
- Wandering, exit seeking
- Fidgeting
- Hiding, hoarding items
- Perseveration (clapping, tapping)
- Eating inedibles (soap, dirt, feces)
- Inappropriate dressing, or undressing
- Interfering with other residents
- Tugging at restraints
- Inappropriate voiding/defecation
- Sexual disinhibition
- Nervousness, restlessness

Responsive Behaviours – looking for a cause

1. Clarify and describe the behaviour
   - Timing, frequency, severity, triggers, consequences
   - Tools: Timing (DOS charting), ABC – antecedent, behaviour, consequences
2. What are the risks? (self, others, health, neglect)
3. Identify: what is new, what has changed?
4. Clinical evaluation (PIECES)

Physical

- Delirium
- Disease (CV, infectious, insomnia, metabolic, nocturia, urinary retention, etc)
- Drugs (anticholinergic, psychotropic etc)
- Discomfort (pain, constipation, fecal impaction, urinary retention, hunger, thirst)
- Disability (hearing impairment, visual loss)

Intellectual (7 As)

- Amnesia
- Aphasia
- Apathy
- Agnosia
- Apraxia
- Anosognosia
- Altered perception

Emotional

- Disorder Adjustment
- Disorder of mood (anxiety, depression)
- Delusion
- Disorder of personality

Capabilities

Capabilities too low to meet the demands of the environment (catastrophic reactions or bored). Maximize remaining strengths

Environment

- Over/under stimulation, relocation, noise, lighting, colours, social interactions

Social

- Cultural background, history, heritage

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Clinical evaluation

- Vitals: incl Orthostatic vitals
- Physical: signs of constipation, urinary retention, pain, CHF (? PND, orthopnea, edema)
- Common sources of pain: skin, ulcers, eyes, msk, feet, oral, dental
- Sensory: hearing, (wax, aids), vision (check up)
- Mental status evaluation (GDS, Cornell)

- Blood: CBC, electrolytes, BUN, creatinine, glucose, calcium, ferritin, TSH (as appropriate)
- Urine R & M, C& S
- Recent changes:
  - Drugs, environmental, routine, family, medical
- Imaging: as appropriate

Treatment

- Individualized non-drug therapy
- Treat identified conditions (pain, constipation, etc.)
- Consider drug treatment if:
  - Psychosis (persistent delusions and hallucinations)
  - Imminent risk to self or others (Physical Aggression)
  - Severe / disruptive aggression (Verbal Aggression)
  - Anxiety with restlessness
  - Sadness, crying, anorexia, insomnia if part of depression
  - Apathy (that is causing distress / risk)
  - Sleep disturbance
  - Elation, pressured speech, and hyperactivity (manic like symptoms)
  - Sexually inappropriate behaviour with agitation / aggression

Sleep

Sleep disturbances are common in individuals with dementia

- 50% experience sleep difficulties of some kind
- One study found that up to 70% of family care-givers report night-time difficulties (e.g. wandering at night) played a role in their decision to institutionalize their family member
  - Pollack CP,. *J Geriatr Psychiatry Neurol 1991;* ***4: 204–210***

- Sleep changes in this population include:
  - Decreased total sleep time,
  - Longer time falling asleep
  - More nighttime awakenings
  - More time spent in lighter stages of sleep , and decreased slow wave (deep) and REM sleep
- Result: more sleep fragmentation, increased daytime tiredness and napping, day/night sleep reversals

Strategies to improve sleep in Dementia

Environmental Modifications	Behavioural Modifications
Minimize nighttime noise and light	No caffeine (chocolate, tea, coffee) for 6 hours before sleep
Maintain a consistent bed and rising time Keep sleeping areas dark at night	Minimize alcohol or tobacco use, and none < 3 hours before bed
Use nightlights to avoid use of overhead lights when getting up at night	Reduce late night (after 6pm) fluids to avoid waking up a night to void
Use the bed only for sleep (not TV, reading)	Empty bladder before bed
Make sure hallway lights (streetlights, bathroom lights) are not shining in their eyes	A light snack before bed can reduce awakenings because of hunger
Sleep with the radio/TV turned OFF (unless relaxation techniques work, ie. Meditation tapes)	Exercise regularly, but be sure to finish 3 hours before bedtime
Avoid medications that affect sleep.	Limit daytime naps to 1 in early am or afternoon
Treat Pain	Spend time during the day in natural light /sun

Outline Sleep History (diary)

Patient Daily Sleep Diary

- What time did the patient go to bed last night?
- What time did he/she get out of bed this morning
- Did he/she make any trips to the bathroom last night (or feel like they needed to)
- Describe any unusual nighttime activity (i.e. wandering) that occurred during normal bedtime hours (including the times they occurred)
- Did they nap yesterday?
  - If Yes, how many naps? Approximately what time did each nap start/stop?
- Did he/she take anything to help him/her sleep or reduce agitation?
  - Name _____ - Dose _____
- How would you rate their sleep last night?
  - Poor night with no sleep or very little sleep (<2 h)
  - Difficult night with little sleep (2–4 h)
  - Fair night with multiple brief (< 30 min) awakenings > 4 h total sleep
  - Good night with only one brief (< 30 min) awakening

Sleep Treatment

- **RCT evidence for melatonin 2mg improved sleep efficiency, well tolerated (1)**
- **Systematic review evidence reduces sleep latency (2) in mild stage Alzheimer's**
- **Meta analysis (3) : melatonin up to 10 mg (nine studies) no evidence for efficacy; no evidence for benzo and non-benzos; minimal evidence for trazadone 50mg**

1. Wade et al. Clin Interv Aging 2014; 9:947-61
2. Blackman et al . J Sleep Res 2021 Aug;30(4):Epub 2020 Dec 2.
3. McCleery et al. Cochrane 2020 Meta analysis

Apathy

Apathy

- Loss of motivation (“can’t be bothered” phenomenon)
- Like inertia
- Manifests as:
  - Diminished initiation, indifference, low social engagement, blunted emotional response
- Often confused with depression
  - About half of AD patients with apathy have no depression.
- Affects:
  - 42% of mildly cognitively impaired patients
  - 80% of moderately cognitively impaired patients,
  - 92% of severely cognitively impaired patients.

Apathy
A source of caregiver burden

- Require more management and support because they rely on others to initiate behaviours even when they are still capable of performing the activity.
- Caregivers may misinterpret apathy as laziness, fatigue, or deliberate opposition.
- Caregivers will often report that patients are less spontaneous, interactive, and affectionate.
- There is less involvement in household chores, self-care, recreation, and socializing.

Screening questions:

- Has the patient lost interest in the world around him/her?
- Has he/she lost interest in doing things or lack motivation for starting new activities?
- Is he/she more difficult to engage in conversation or doing chores?
- Is the patient apathetic or indifferent?

If YES to any of the above, the following subquestions are asked:

1. Does the patient seem less spontaneous and less active than usual?
2. Is the patient less likely to initiate a conversation?
3. Is the patient less affectionate or lacking in emotions when compared to his/her usual self?
4. Does the patient contribute less to household chores?
5. Does the patient seem less interested in the activities and plans of others?
6. Has the patient lost interest in friends and family members?
7. Is the patient less enthusiastic about his/her usual interests?
8. Does the patient show any other signs that he/she doesn't care about doing new things?

Strategies to managing apathy

- Mainly caregiver education (90% of the time this is all that is needed)
- Direct prompting
  - I.e.. Not “do you want to go for walk” – instead “we are going for a walk now”
- To initiate activities, using visual cues to behaviors
- Set up routines for daily activities.
- Apathetic individuals may also benefit from heightened levels of social stimulation.
- Music (live > pre-recorded)
- Medications (rarely: cholinesterase inhibitors, memantine, methylphenidate)

Psychosis, Agitation, Aggression

Non responsive to non-pharm

Monitor and document

- Determine therapeutic goal (what am I targeting)
- Consider antipsychotic medication:
  - Psychosis, risk of self harm, or to caregiver, severe disruption
  - Is there time? (consider safer alternatives: citalopram, trazadone)
- Expect limited effectiveness
  - effect size 0.12-0.2 (10-20%) ; NNT 5-14
  - At best, results in targeted behaviour improvement in 1 out of 5
- Assess Capacity and Communicate risks:
  - Sedation, confusion, falls, OH, QT prolongation, EPS, urinary retention, aspiration
  - ARI of stroke, all cause mortality 1.5%
    - Baseline risk goes from 1.5 to 2.9% (essentially doubles the absolute risk) – (CHF, sudden death, pneumonia). NNH 1 in every 100 treated for 12 weeks.
- Monitor and document effectiveness
- Review and attempt deprescribing q 3 months

	Drug Generic (Brand)	Efficacy or evidence in BPSD therapy	↓ BP[32]	Ach	Sedation	EPS	TD[33]	Diabetes	Weight Gain[27]	Usual Dose	$/M
Atypicals	Risperidone* (Risperdal)[25, 26, 34]	✔Indicated for severe dementia of the Alzheimer type(Health Canada) • Evidence for efficacy in agitation, aggression & psychosis	++	++	++	++	+	++	↑↑↑ (0.7lb/ month)	0.125mg – 2.0mg/d QHS (or divided BID)	$1
	Olanzapine* (Zyprexa)[25, 26, 34]	• Off-label use in BPSD • Evidence for efficacy in agitation & aggression	+	+++	+++	++	+	+++	↑↑↑ (1.0lb/ month)	1.25mg – 7.5mg/d	$
	Aripiprazole* (Abilify)[34]	• Off-label use in agitation or aggression[18] • Evidence for efficacy in agitation & aggression • Not eligible in ODB for dementia or BPSD in the elderly • Not for psychosis(same as placebo)	+	+	++	+	+	–	↑	2.0mg – 12.5mg QHS	260
	Quetiapine (Seroquel)[25, 26, 34]	• Off-label use in BPSD • Lacks evidence for efficacy in BPSD agitation, aggression, or psychosis • Consider in Lewy Body dementia, Parkinson's (low EPS) • Note: although used, not indicated and lacking evidence for insomnia	++	+++	+++	+	+	+++	↑↑ (0.4lb/ month)	12.5mg – 200mg/d (divided QHS-TID)	$10-59
Typicals	Haloperidol (Haldol)	• Useful short term in acute BPSD or delirium	+	+	+	+++	+++	++	↑↑	0.25mg – 2mg/d	$14-25
	Loxapine (Loxapac, Xylac)[2]	• Consider if other agents have failed and severe persistent dangerous behaviour continues • Severe, acute BPSD • Not to be used long-term due to adverse effects	++	++	+++	+++	+++	+	–	5mg – 10mg BID	$18-27

Frequency of ADEs at therapeutic doses:
-: Negligible
+: Infrequent (> 2%)
++: Moderate (< 10%)
+++: Frequent (>30%)
↑: Increase

Centre for Effective Practice; Use of Antipsychotics for Behavioural and Psychological Symptoms of Dementia Discussion Guide; Sept 2015 Version 1

Reassessing/Deprescribing

- **Consider dose reduction or discontinuation if :**
  - **Not effective**
  - **Intolerable side effects (watch for akathisia)**
  - **Behaviours manageable, especially q3-6 months**
    - Individual decision – may not be reasonable if behaviour severe
    - Optimize non-pharm approaches, remove triggers
    - As behaviours “responsive” , antipsychotics can typically be safety discontinued if triggers removed, or 3-6 months (as behaviours tend to cycle q3 months)
  - **Need monitoring, approach cautiously**
  - **Taper by 25-50% q2-4 weeks. At lowest dose, leave for 2-4 weeks, then stop.**
  - **Reassess often, allow caregivers quick access to PRNs**

Part 2 – Modifying the Home Environment to Increase Safety for a Patient with Dementia

Breanne Chohan OT Reg. (Ont.)

Sources of Risk in Persons with Dementia

The value of a home visit

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The value of a home visit

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Who are your eyes in the home?

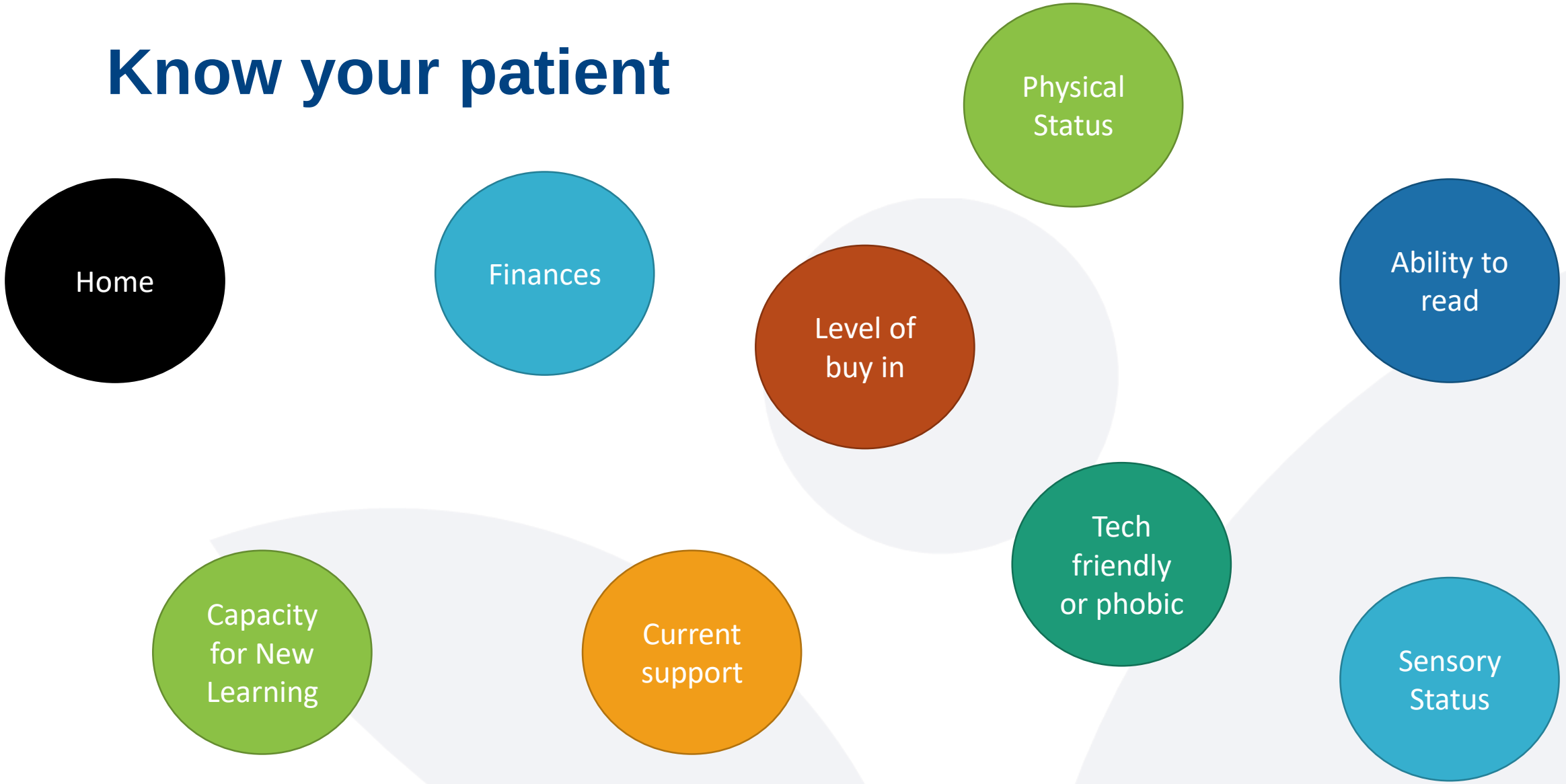
Family
Friends
Neighbours

Home Care (Nursing, PSWs etc.)
Allied Health (OT/PT/SW/SLP etc.)
Community Paramedics
Alzheimer's Society, BSO etc.

Contractors
Cleaning personnel
Landlords

(Within the bounds of confidentiality……)

Know your patient



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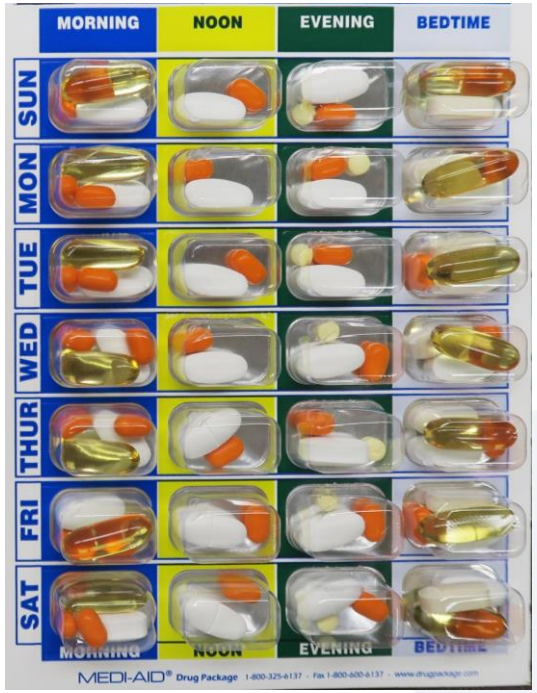
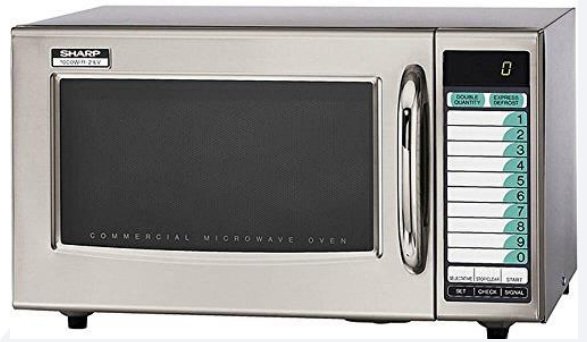
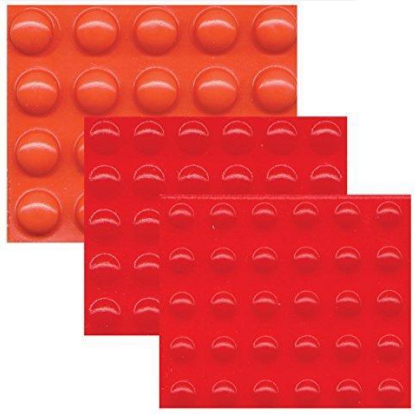
Medications



The Kitchen





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Bathroom

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Falls


Reset


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Fire/Burns

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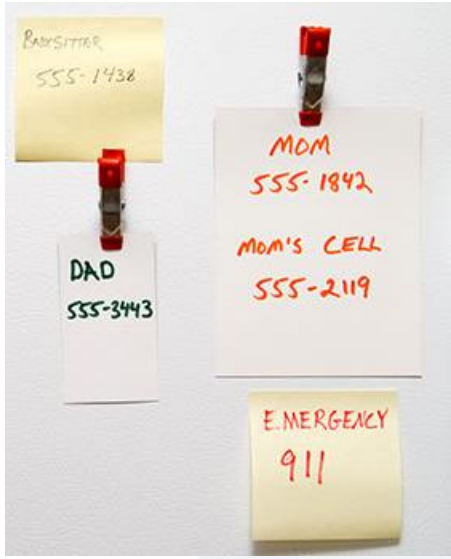
General Safety



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Part 3 – Case Study

Dr. Jo-Anne Clarke

Case Studies

1) Fire drill
2) New increase agitation
3) Use restraint
4) Repetitive floods

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