

# From Both Sides Now:

## Lessons from life as a family care partner

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# Presenter:

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## DECLARATION & AFFILIATION

- I AM SPEAKING AS A FAMILY MEMBER, NOT A PROFESSIONAL
- NO CONFLICT OF INTEREST TO REPORT
- ADJUNCT LECTURER APPOINTMENT WITH THE U OF T DEPARTMENT OF OCCUPATIONAL SCIENCE AND OCCUPATIONAL THERAPY

# Speaker Background

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OT working in outpatient Neuro Rehab since 2002

- Roles in outpatient ABI rehab and LEAP Pain Service
- Some inpatient unit pandemic redeployment

Masters in Adult Education

Close family member sustained a TBI in summer 2023

Health info shared with permission of family



# Objectives of session

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Review health journey

Lessons learned:

1. Educate everybody
2. Recognize delirium
3. Recognize pain
4. Help people feel safer
5. Do what matters
6. Train the family
7. Infection control
8. Prepare for emergencies
9. Your work matters
10. Practice gratitude

*Trigger warning!*

# HEALTH HISTORY REVIEW

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# LESSONS LEARNED

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# 1. Educate **everybody**

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# Our experience: Educate everybody

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My family were well situated to understand health info

We still had trouble getting clarity and understanding what info meant to us – stress, volume of information

“Cast of thousands” of care providers

Multiple moves within and between hospitals

Great pragmatics masked poor comprehension



# Our experience: Things we wanted to know

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When should I call for assistance? Red flag symptoms

Schedule & plans: What's likely to happen next?

Basic orientation: where to eat, use bathroom

How can I help?

# Evidence: Health Literacy

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Health literacy: how well people can get, process, and understand the info they need to make health decisions

30% of people have insufficient health literacy

40-80% of health info is forgotten

50% of retained info is incorrect

“Universal precautions” wise

Inpatients with ABI and families say info is a key need (Fleming et al, 2012)



# Practice tips

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Identify your role often! Like a reverse PPID check

Don't rely on online patient portal – info hard to find

Avoid the “broken telephone” of info relaying within family

Make consent moments obvious

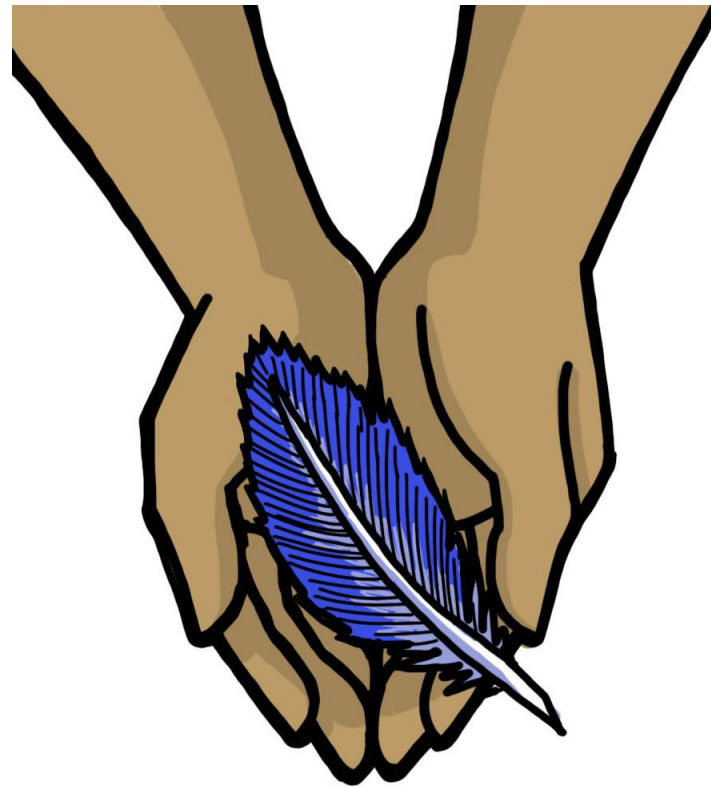
Post schedule, alert about appointments

Use teach-back, plain language and written info

Help family understand ABI symptoms

## 2. Recognize delirium

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# Our experience: Delirium

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Delirium was a major barrier to progress

At best, she was present and interactive

At worst, profound impairment (hypoactive type)

Unable to call for help

Paradoxical fatigue: more activity = more energy

It took time to understand it as separate from brain injury

Even after stable, noticed signs at times



# Evidence: Delirium

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Manifestation of stress on CNS function

Acute change to attention, thinking and LOC; fluctuating course

Types:

- Hyperactive: agitation, hallucination, delusions, behaviour
- Hypoactive: decreased arousal, sleepy; Harder to catch; riskier
- Mixed: Fluctuating between the above types

Seniors with neuro issues and surgery at particular risk

Consequences: mortality (2-4x increase), falls, malnutrition, lost function, pneumonia, cognitive impairment, PTSD, mood disorders

# Evidence: Delirium

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## Treatment:

- Mobilize and activate early
- Orient
- Train family on how to help
- Reduce stress; quiet and calm environment
- Manage pain, nutrition, hydration, sleep, bowel/bladder
- Provide glasses / hearing aid

# Practice tips

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Watch out for delirium – identify early

Get patients doing activity and out of bed ASAP

Explain what's happening to patient and family so they can understand which symptoms may be temporary

Monitor carefully if unable to access call bell

Recognize that patient may take in more than is obvious



3. Recognize pain  
(and do something about it)



# Our experience: Recognize pain

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Post-operative pain at surgical sites

Contributed to delirium

Signs: furrowed brow, agitation, Lamaze breathing

Needed help to ask for relief: “Do you need anything?” “No.” vs “Do you want pain medicine?” “Yes!”

Leg / back pain started 7 weeks in, once more active

Never refused therapy! But lots of people do



# Evidence: Pain and ABI

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More than 50% of clients with ABI have pain

- (Khoury & Benavides, 2018); Nampiaparampil, 2008)

People with ABI report less control over pain than others

- (Dahm & Ponsford, 2015; Branca & Lake, 2004; Tyler & Lievesley, 2003)

Fear and avoidance of movement can escalate (Leeuw et al, 2007)

Self-management education works!

- (*Hoffman et al., 2007; Mann, LeFort & VanDenKerkhot, 2013; Nash, Ponto, Townsend, Nelson & Bretz, 2013*)

Education about pain for adults with ABI associated with improved participation in rehab, outcomes, less anxiety and fear of movement

- (Williams, Rapport, Sander & Parker, 2021)

# Evidence: Best pain coping skills



Adaptations for ABI:

- Clear language
- Structure (checklists)
- Repeat key ideas
- Procedural practice
- Info in writing / media



# Practice Tips

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Watch for non-verbal cues of pain

Don't be afraid to ask about pain- acknowledging helps

“Lean in” to coping strategies client already knows

## Try strategies from the “big 3” types:

1. **Distraction:** heat, cold, massage, reading, games
2. **Calming:** music, social support, relaxation techs, breathing
3. **Movement:** Challenge the pain with gentle activity

## 4. Help people feel safer



# Our experience: Help people feel safer

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Experiencing and witnessing critical illness was stressful – uncertainty, big decisions, many setbacks

Exposure to critical care environment

Moving between rooms, floors, and teams

Physical reminders of injury

Difficulty showed up in unexpected moments

# Evidence: Trauma Informed Practice

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Assume everyone could have trauma

Be aware of signs of fight / flight / freeze behaviour

Calmer people can reason and communicate easier

You don't have to treat the trauma, but you can help by creating a safer atmosphere, and being understanding

Support client's autonomy, sense of control (Davies, 2023; O'Hanlon, 2022)

“Mobile mourning”: severe loss and prolonged uncertainty can lead to disorganized, fluctuating grief (Muir, 2016)





# Practice Tips

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Watch for **“complicated course in hospital”**

Welcome comforting visitors and decorations

Set up environment for care that feels safer

Minimize changes of staff and room

Point out where person has choice and control

Explain the schedule, goals and next steps

Co-regulate: provide calm and caring non-verbal cues

Build in calming strategies if appropriate

# 5. Do what matters



# Our experience: Doing what matters

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The power of meaningful activity: quality of life comes from doing things that matter with people that matter

Making coffee with OT

Going outside for walks, into green space

Visiting everyday settings like farmers market, cafe

Spending time with family and friends

Familiar comforts: reading, crossword

# Evidence: Doing what matters

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Engaging in personally meaningful activities, especially with family, linked to positive health outcomes and sense of self

Neuroplasticity in early healing is strongest when doing activity in an enriched environment

Boredom, isolation and inactivity are common for inpatients

However, restful activities have value; clients get tired!

People want to go **outdoors** and off unit



# Practice tips

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Take the time to get to know who and what is most important to your patient

Draw connections between therapy activities and valued things and people

Help client structure valued leisure activity for down time

Tell people how to go off unit & outdoors

## 6. Train the family



# Our experience: Train the family

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Taking action provided sense of control

Empowering moments: Walking on weekends, going off unit, bringing in food, looking up resources...

Discharge feels big and unknown— time and information needed to prepare resources and environment

Team-Family Conference, discharge planning conversations were very valuable



# Evidence: Family caregivers

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Family help influences health outcome: more access to services, activity engagement

Becoming a family caregiver has heavy learning needs:

- Support services
- How to do caregiving tasks

Survivor/caregiver dyads manage the condition together- If either has high self-efficacy, they adjust better





# Practice Tips

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The family IS the discharge plan, so train them to do tasks they will have to do at home

Teach family about community resources and how to navigate healthcare system

Use weekend and day passes to problem-solve

Watch for stress / “mobile mourning”

## 7. Wash your Hands





# Our experience: Infection control

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## Mortality avoided:

- Systemic listeria mortality rate: 39% (Huang, Lu & Yang, 2023)
- TBI mortality rate for elderly: 38% (McIntyre et al 2013)
- Meningitis mortality rate: 44% (Gorse et al., 1984)
- Hyponatremia mortality at 1 yr: 28% (Ioannou et al, 2021)
- Delirium mortality at 1 yr: 44% (To-aditthep et al., 2023)

Tens of thousands of healthcare dollars – Average cost in Canada for 1<sup>st</sup> year post TBI with IP rehab \$93,340 (Chen et al, 2012)

Months of time and work invested

Lost due to a germ

# Evidence: Infection Control

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Hospital acquired conditions are a significant cause of morbidity and mortality worldwide

- In USA: almost 100,000 deaths annually (Bashar, 2019)

50% of hospital-acquired infections preventable (UHN IPAC, 2024)

Cheap and effective solutions: wash hands frequently, clean surfaces, mask, gown and glove as needed

Staff enough nurses! More staff are associated with much lower levels of infection (Bashar, 2019)



# Practice Tips

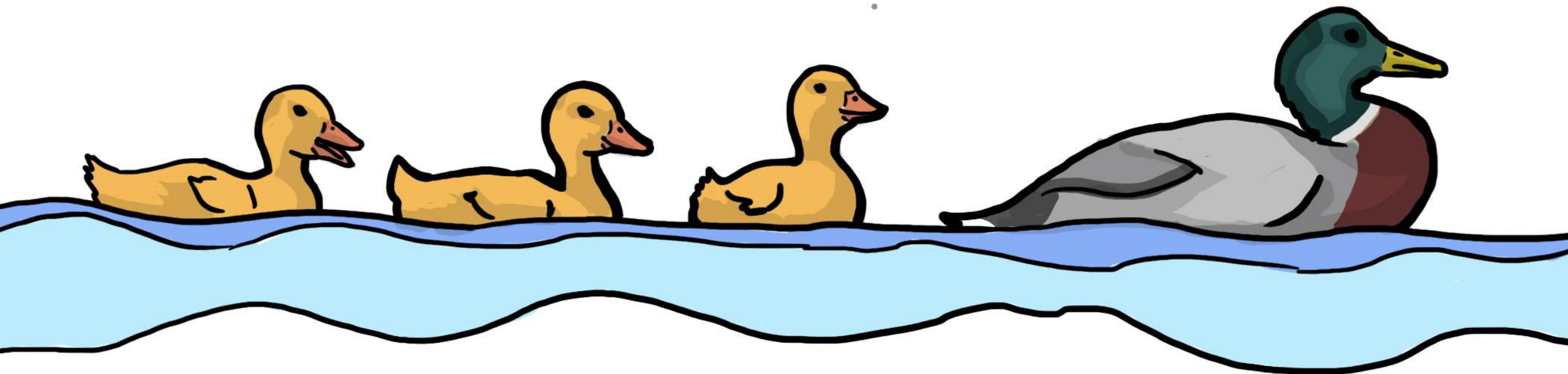
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It's been said so many times... but...

- Wash your hands
- Wipe down equipment
- Wear a mask if you have symptoms

*You might save a life!*

## 8. Get your Ducks in a Row



# Our experience: Get your ducks in a row

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We are all one fall away from a big change in health

We were prepared because of being well oriented to a coherent filing system

Discussions about care wishes in video form were a powerful guide

# Practical Tips

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Discuss emergency care wishes

Set up Power of Attorney for health and finances

Talk to your loved ones about where they keep documents:

- Will, marriage certificate, deed to house
- Lawyer and accountant contact info
- Banking info
- Health insurance info
- Burial plot documents and preferences





## 9. Remember that Your Work Matters



# Our experience: Your work matters!

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We get so used to the routines that we don't see it clearly... but rehab is MAGIC

It is awe-inducing to see your loved one wake up, speak, take their first steps, rise to challenges

The kindness and compassion shown by healthcare providers along the way made a world of difference

# Evidence: Your work matters

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Patients value staff's attentive, caring and encouraging qualities highly (even more than quality of care!) (Jesus et al, 2024)

Positive relationships with hospital staff boosted patients' sense of wellbeing and hopefulness (Lafiatoglou et al., 2023)





# Practice Tips

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Take a moment to step back and feel the wonder sometimes

When people express appreciation, listen mindfully, take time to take it in

Celebrate the successes, and hold struggle with compassion

# Invitation

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A round of applause for all of you, for all you do!





## 10. Enjoy the Strawberries

# Our experience: Enjoy the strawberries

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Even on this difficult health journey, strawberries abounded:

- Wonderful conversations
- Precious time for family togetherness and caring
- Friendships and human connections
- Milestone moments of hope
- Opportunities to learn about life



# Evidence: Gratitude

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It's good for your physical health (Boggiss et al., 2020)

It's good for your brain (Karns, Moore & Mayer, 2017)

It helps you cope and solve problems (Uanue et al., 2017)

It makes you happier (Uanue et al., 2017)



# Practice Tips

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Consider practicing gratitude yourself

Talk about gratitude with your patients and teammates

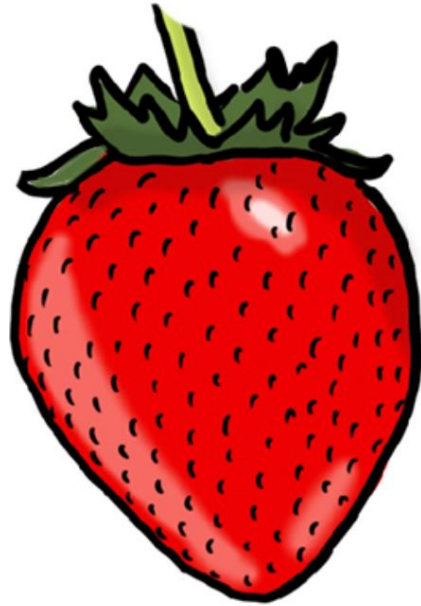
Point out and celebrate even small steps forward

Enjoy the moments of joy and humour together

# Invitation

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What is a “strawberry” for you, in this moment?  
(Something small that you are grateful for)



# WRAPPING UP

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*“I've looked at clouds from both sides now  
From up and down and still somehow  
It's cloud illusions I recall  
I really don't know clouds at all”*

- Joni Mitchell (1969)

*THANK YOU FOR YOUR KIND ATTENTION!*



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