

5Ms: A Framework to Promote Healthy Aging For Adults with Spina Bifida



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Outline

- Discuss the 5Ms of age-friendly care
- Recognize challenges of aging for patients with spina bifida
- Apply the 5Ms to optimize holistic care for older adults with spina bifida



Lisa's Story: Navigating Spina Bifida after 50

- What does life with spina bifida after 50 look like for you?
- Can you share a challenging moment in your healthcare journey?
- What does good healthcare for older adults with spina bifida look like?



Lisa's Story:



Road Maps Across the Spina Bifida Life Span



- Over **85%** of people with spina bifida survive into adulthood.
- By 30 years old:
 - 1/3rd are independent
 - 1/3rd need occasional help
 - 1/3rd need assistance for ADLs due to intellectual disability.
- **By 50, people are... ??**
 - Shunt technology implemented in the 1960s (**66 years ago**).
 - CIC was introduced in 1972 (**54 years ago**).
 - Continued orthopedic and neurosurgical advances.

Szymanski et al. J Ped Rehabilitation Medicine. 2023; 16 (605-6019.

5 Denis et al. Childs Nerv Syst (2010) 21: 1749-1755.

Wood et al. Journal of Pediatric Rehabilitation Medicine. 2019; 12 (3): 211-220.

Problem Based A&P

Medication
reconciliation

Preventative
Screening

Caregiver burden

Advanced care
planning

Patient priorities

Mental & Cognitive Health

Neurogenic
Bladder

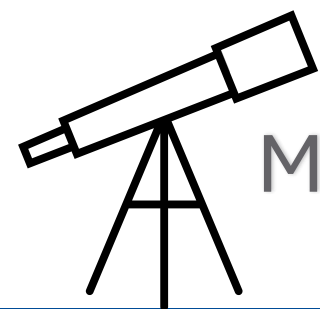
• Differential
Plan

Pressure
Ulcer

• Differential
Plan

Hypertension

• Differential
Plan



5Ms Framework



Credit: **Age-Friendly Health Systems**

An initiative of the The John A. Hartford Foundation and the Institute for Healthcare Improvement (IHI) in a partnership with the American Hospital Association and the Catholic Association of the United States (CHA).

> Clin Transl Gastroenterol. 2022 Jan 12;13(1):e00445. doi: 10.14309/ctg.0000000000000445.

The 5Ms of Geriatrics in Gastroenterology: The Path to Creating Age-Friendly Care for Older Adults With Inflammatory Bowel Diseases and Cirrhosis

Bharati Kochar ^{1 2 3}, Nneka N Ufere ^{1 2}, Christine S Ritchie ^{2 3 4}, Jennifer C Lai ⁵

Clinical Interventions in Aging

Dovepress
Taylor & Francis Group

Open Access Full Text Article

REVIEW

Using the 5Ms Framework to Advance Aging-Responsive Care for Heart Failure with Reduced Ejection Fraction

Review > Lancet Rheumatol. 2024 Dec;6(12):e892-e902. doi: 10.1016/S2665-9913(24)00230-3.

Epub 2024 Nov 11.

Understanding the multiple dimensions of ageing: 5Ms for the rheumatologist

Bjoern Buehring ¹, Marloes van Onna ², Elena Myasoedova ³, Jiha Lee ⁴, Una E Makris ⁵

> Can J Anaesth. 2022 Sep;69(9):1080-1085. doi: 10.1007/s12630-022-02270-9. Epub 2022 Jun 10.

Applying the geriatric 5Ms in critical care: the ICU-5Ms

Olivia Geen ¹, Andrew Perrella ², Bram Rochweg ^{3 4}, Xuyi Mimi Wang ⁵

> Gerontol Geriatr Educ. 2026 Jan-Mar;47(1):90-94. doi: 10.1080/02701960.2024.2395258. Epub 2024 Aug 29.

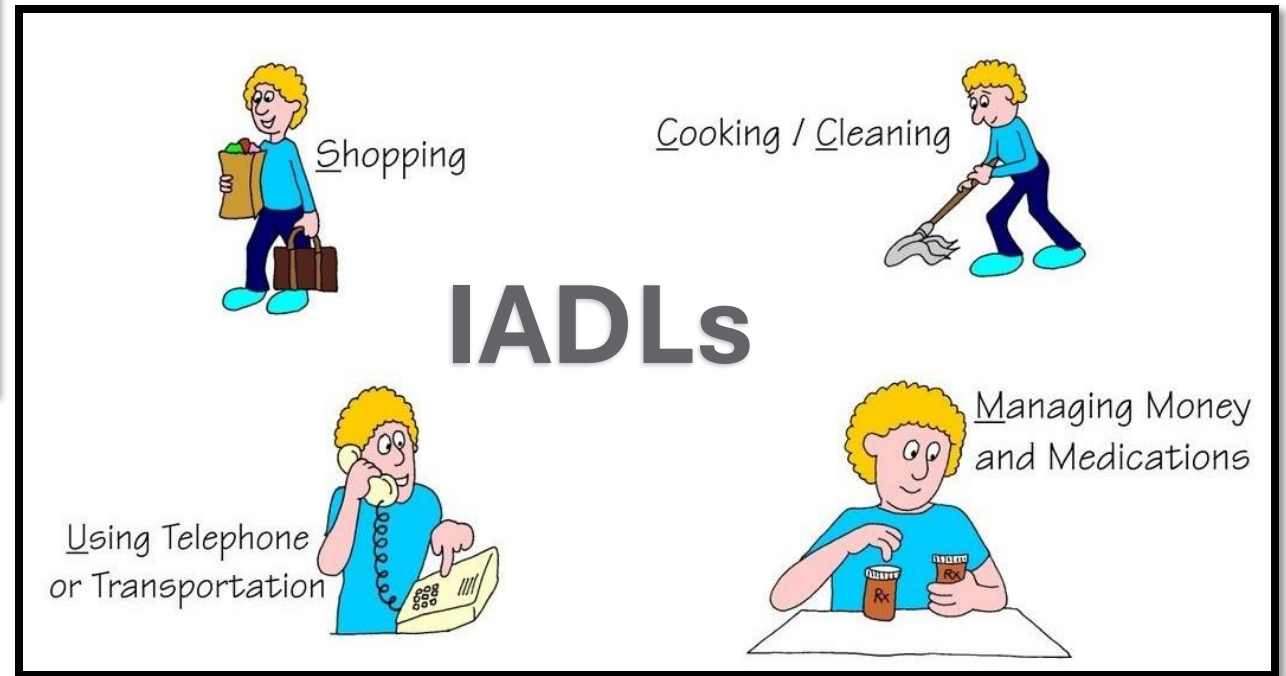
An age-friendly opioid use disorder (OUD) care workshop: Applying the 5Ms framework

Kimberly J Beiting ¹, A Justine Landi ², Vassiliki Pravodelov ³, Mim Ari ⁴

Mobility



Mobility: Understand Baseline Function

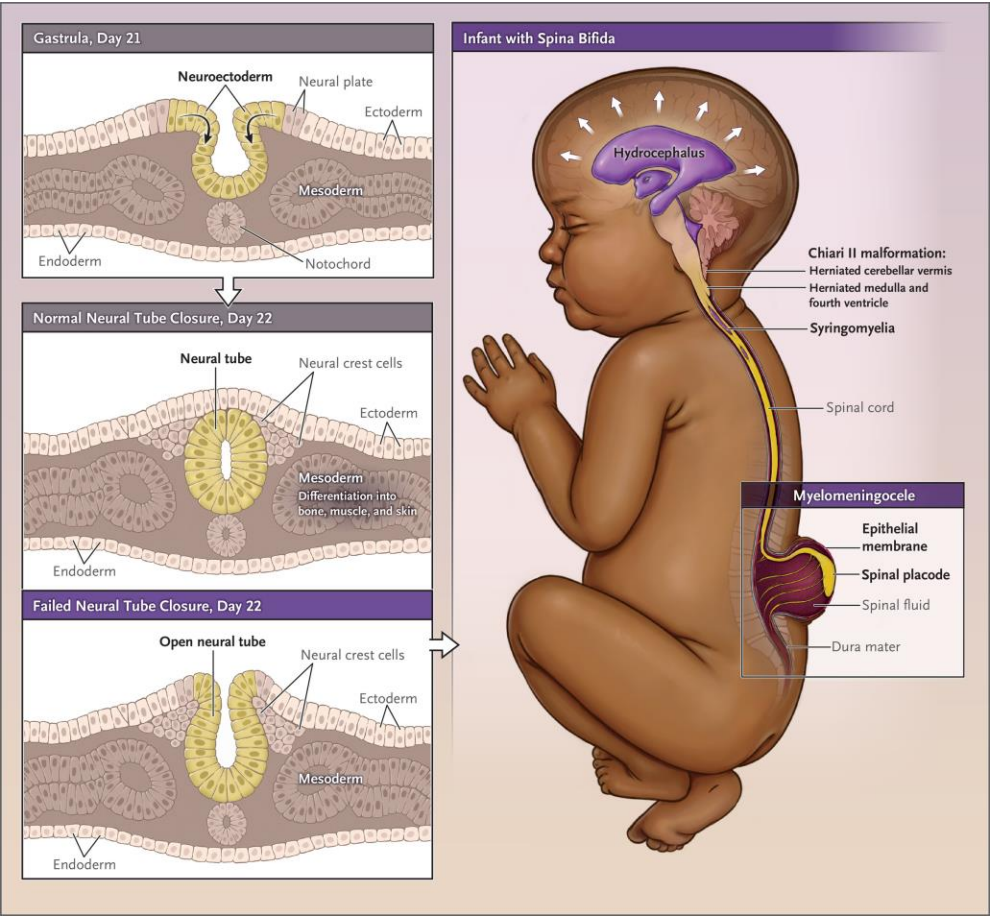


Frailty

- Chronological age vs. physical age
- Higher risk for complications
- Higher mortality rate

FRAILITY SCORE: OPERATIONAL DEFINITION ⁸⁹	
Criteria	Definition
Shrinkage	Unintentional weight loss ≥ 10 pounds in past year
Weakness	Decreased grip strength
Exhaustion	Self-reported poor energy and endurance
Low physical activity	Low weekly energy expenditure
Slowness	Slow walking
Interpretation of the Frailty Score	
The patient receives 1 point for each criterion met.	
0–1 = Not Frail	
2–3 = Intermediate Frail (Pre-frail)	
4–5 = Frail	
Frail patients are at much higher risk of adverse health outcomes.	
Intermediate frail patients are at elevated risk (less than frail ones) but are also at more than double the risk of becoming frail over three years.	

Spina Bifida & Mobility



Muscle Function	Level	Expected Mobility
Other Factors Influencing Mobility: - Spasticity at the knee & Hip - Shunt Revisions - Balance Disturbance - Obesity**		Community Ambulation
		Orthosis & WC for long distances
		Household ambulation with orthosis and walking aid; WC long distances
		Orthosis and walking aid short distances; WC in-and outdoors
		Non-functional ambulation; WC for mobility

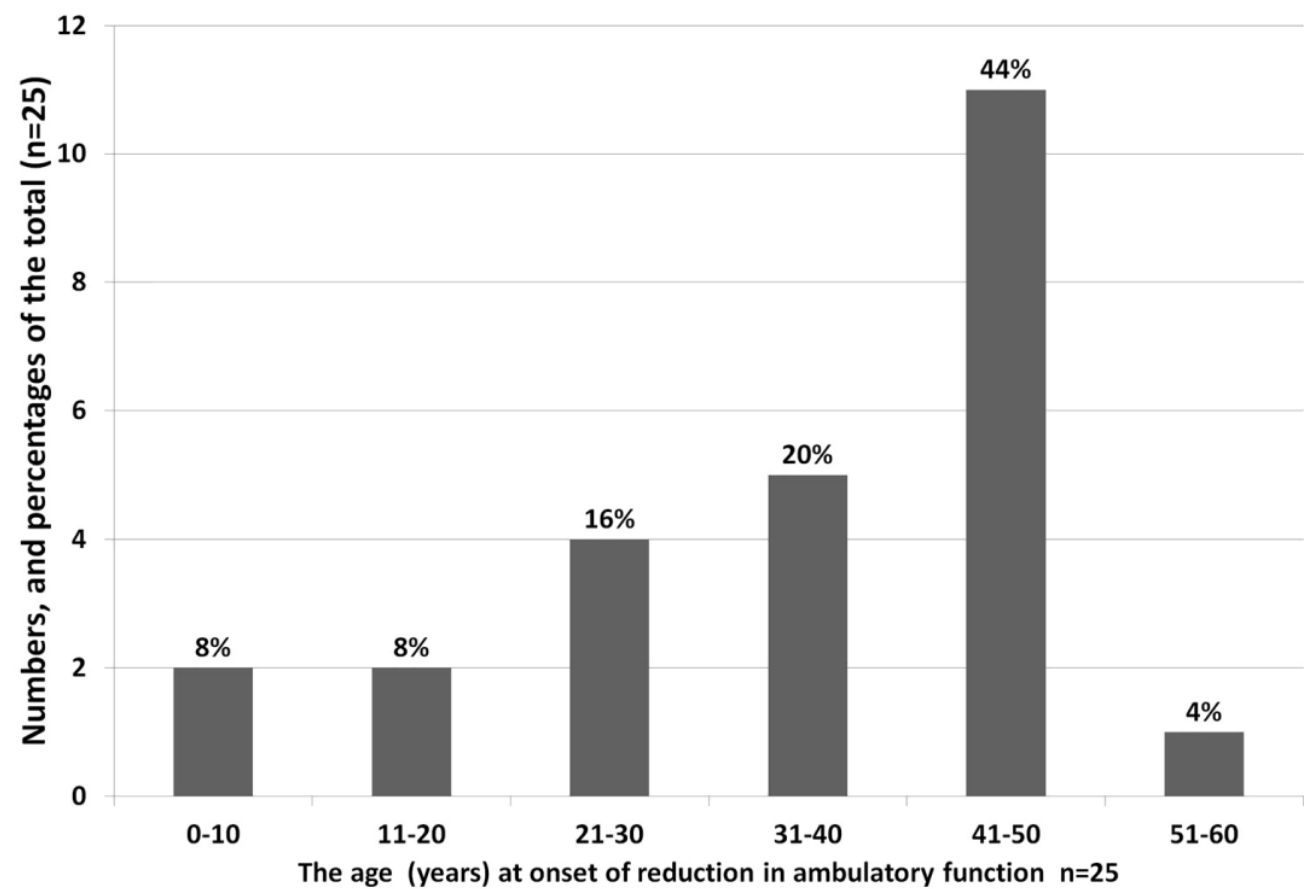
50 Years and older – born with spina bifida: participation, health issues and physical function

30 people with Spina Bifida in Norway who volunteered for study

Mean Age: 57 (range 51-76)
80% without hydrocephalus

45% said their health is somewhat or much worse than a year ago.

Median age of perceived deterioration of walking: 40 years old



50 Years and older – born with spina bifida: participation, health issues and physical function

Predictive Factors for Community Walker Status:

- 1. Sacral SB
- 2. BMI <30 (OR 6.8)

Table 5. Physical function: self-reports and physical performance tests of the total study sample and according to BMI groups.

Variable	Total	BMI < 30	BMI ≥ 30
Community walker <i>n</i> (%)	16 (53)	12 (75)	4 (31) ^c
Physically active > 150 minutes ^b per week <i>n</i> (%)	11 of 24	9 of 14	2 of 10
Reasons for physical activity <i>n</i> (%)			
-QOL/mental well-being	8 of 24	7 of 14	1 of 10
-Pain reduction	2 of 24	2 of 14	0
-Stay fit or maintain function	14 of 24	5 of 14	9 of 10
6MWD in meters; mean (sd); (<i>n</i> = 12 with BMI < 30; <i>n</i> = 6 with BMI ≥ 30)	398.7 (139.7)	446.4 (120.4)	303.2 ^d (134.6)
range	200–723	300–723	200–565
TUG mean (sd); (<i>n</i> = 12 with BMI < 30; <i>n</i> = 8 with BMI ≥ 30)	15.5 (6.8)	12.3 (3.4)	20.3 (7.9) ^e
range	8.1–33.0	8.1–18.1	8.6–33.0

Pain in Older Adults with Spina Bifida

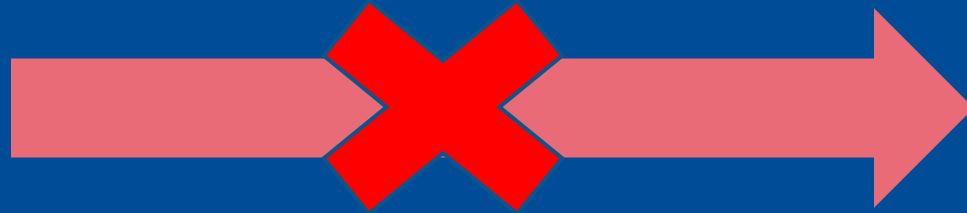
	Perceived presence of condition	Perceived condition as somewhat or greatly impacting daily life
	<i>n</i>	%
Pain	65	90%
Wrist pain ^a		32%
Neck pain		51%
Shoulder pain		54%
Back pain		71%
Knee pain		32%
Hip pain		38%
Other area of pain ^b		24%

In a study of adults (mean age 33 yo) at a multidisciplinary Spina Bifida clinic, **90% of patients reported pain in the last year, most with an impact on daily life.**

- In a study of 48 adults (ages 19-56, mean **30**):
 - **73%** reported pain in the **prior 4 weeks**
 - 67% reported pain at the time of the study.
 - **Upper body** (back, shoulder, neck) pain was the most common.

Mobility Goals in Adulthood

Normalization
of function



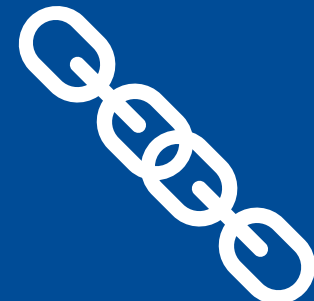
Accommodation
AND Preservation
of function

DME & Therapy: A Team Approach
PM&R, Seating, SW, PT & OT +/-
SLP

ChoosePT™
Provided by APTA

<https://aptaapps.apta.org/APTAPTDirectory/FindAPTDirectory.aspx>

Assess for pain and manage metabolic
health.



Mobility - Spina Bifida Targeted Assessment

☐ ADL/iADL Needs

- Frailty Screening
- Caregiver Assessment
- Home Health/ PT/ OT/ST reassessment?

☐ Gait Assessment

- Falls?
- 6 minute Walk test

☐ DME Assessment

- Wheel Chair
- AFOs
- Shower Equipment
- Adaptive Vehicles

☐ Weight & Physical Activity Screening

- 150 minutes weekly
- Community resources

☐ Pain Screening

- Overuse Injury
- Spasticity
- Fractures

☐ Skin Breakdown & Pressure Wound Assessment

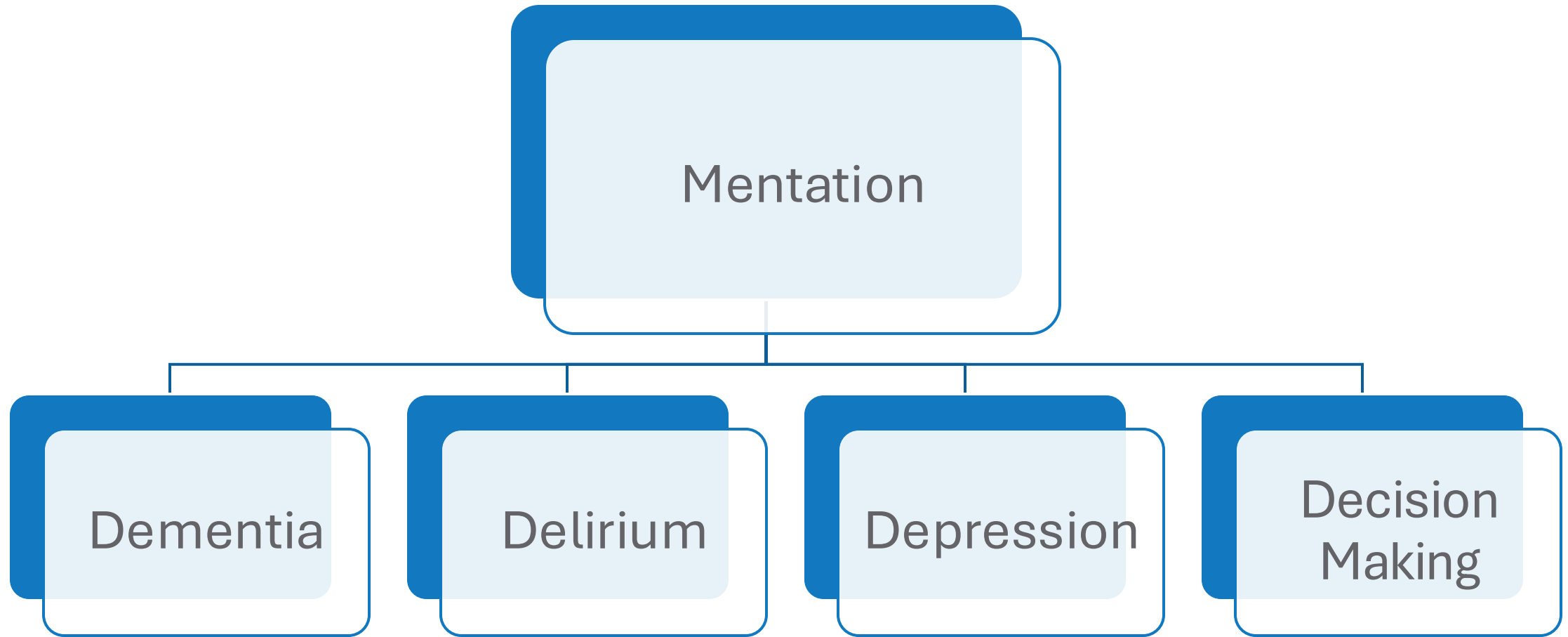
Mentation



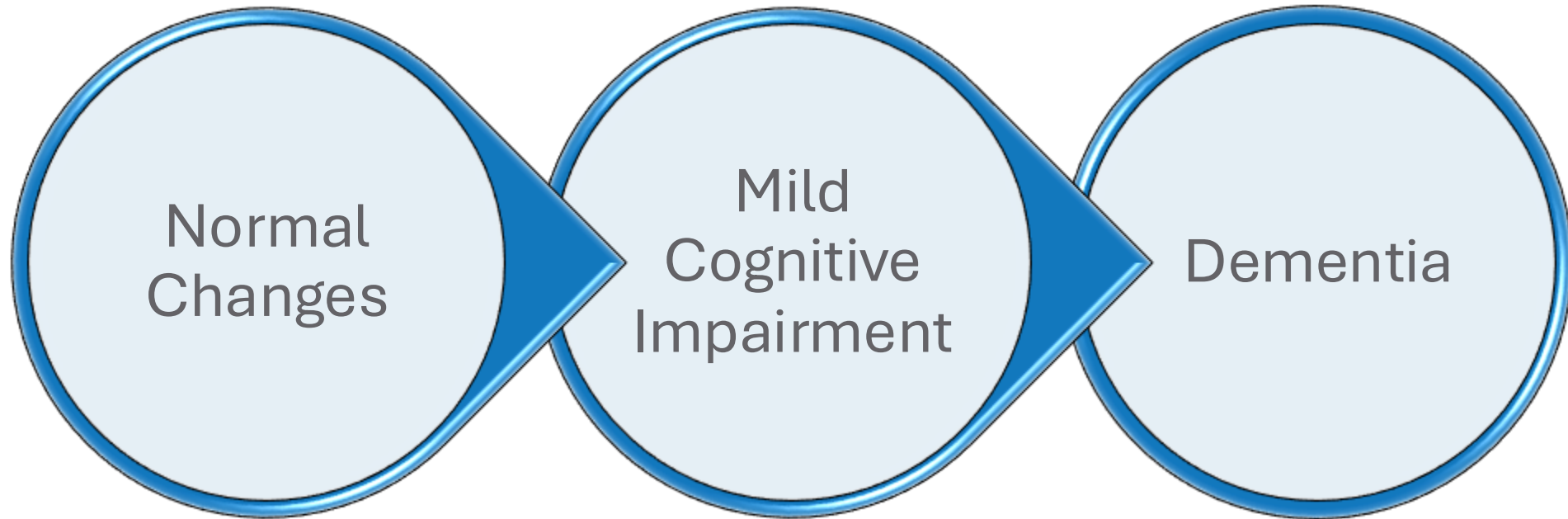
Cognition in Adults with Spina Bifida

- Adults with SBM with hydrocephalus have poorer memory than adults with occulta spina bifida.
- Higher lesions, Chiari II, and Hydrocephalus have more impact on brain function and cognitive morbidity in children.
- Young adults (<35) with SBM demonstrated poorer working memory, attention, and executive function.
- There is unclear data on shunts and cognitive function and memory.
- **Changes in cognition should prompt assessment.**

Mentation

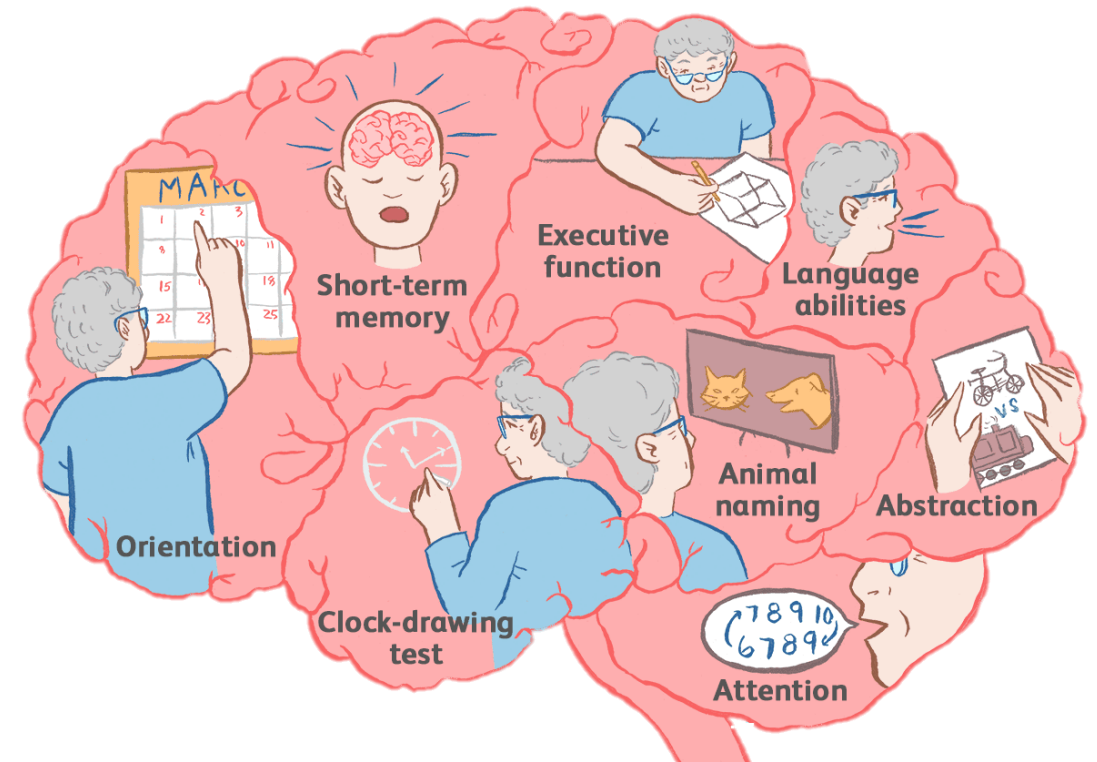


Cognitive Impairment



Assessing Cognitive Impairment

- Mini-Cog
- MoCA
- SLUMS
- MMSE
- Formal Neuropsych Testing



Delirium



BEST PRACTICES IN NEUROLOGY

Recommendations from the Choosing Wisely Campaign

RECOMMENDATION

Do not presume a diagnosis of dementia in an older adult who presents with an altered mental status and/or symptoms of confusion without assessing for delirium or delirium superimposed on dementia using a brief, sensitive, validated assessment tool.

Depression in Older Adults

- Screen for depression and anxiety
 - May present differently in older adults (apathy, weight loss) or people with intellectual disability.
 - No recommended screening tool specific to Spina Bifida.
 - Geriatric Depression Scale (GDS)
- Think about caregiver burden

Mental Health in Older Adults with Spina Bifida

Table 2. HADS results in the SB-population ($n = 30$) compared to (1) mean expected scores ($n = 40\ 646$)* and (2) mean scores in an ageing spinal cord population ($n = 153$)**.

	SB mean (SD)	Expected mean (SD)*	Mean difference	95% CI	p-Value	Effect size
HADS-T	9.87 (6.13)	7.68 (5.66)	−2.19	−4.22 to −0.16	0.034	0.39
HADS-A	5.8 (3.82)	4.40 (3.46)	−1.40	−2.64 to −0.16	0.0265	0.40
HADS-D	4.0 (3.16)	3.30 (2.96)	−0.70	−1.76 to 0.36	0.195	0.24
	SB mean (SD)	SCI mean (SD)**	Mean difference	95% CI	p-Value	Effect size
HADS-T	9.87 (6.13)	5.8 (5.02)	−4.07	−6.12 to −2.02	0.0001	0.78
HADS-A	5.8 (3.82)	3.60 (3.20)	−2.20	−3.50 to −0.90	0.001	0.67
HADS-D	4.0 (3.16)	2.20 (2.60)	−1.80	−2.86 to −0.73	0.001	0.67

36% of adults over 50 with SB had positive depression or anxiety screens. Only 2 were accessing psychiatric care. None were on medical treatment.

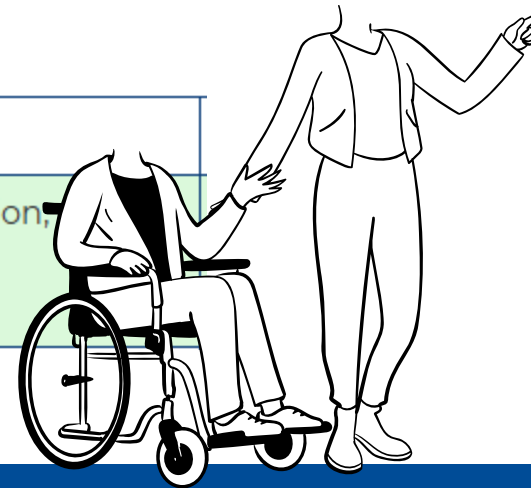
Mental health guidelines for the care of people with spina bifida

18+
years

1. Screen for depression or anxiety and initiate interventions when appropriate.



Population	Recommendation
Adults, including pregnant and postpartum persons, and older adults (65 years or older)	The USPSTF recommends screening for depression in the adult population, including pregnant and postpartum persons, as well as older adults.



Capacity for Medical Decision Making

- Understanding of condition & treatment options
- Reasoning of risks and benefits
- Appreciation of how it applies to an individual
- Expression of a Choice

Table 1: Health care decision-making approaches involving adults with IDD

 PATIENT IS CAPABLE OF MAKING THE DECISION		 PATIENT IS INCAPABLE OF MAKING THE DECISION
INDEPENDENT The patient can provide appropriate information to the health care clinician performing the capacity assessment without the assistance of a decision-making supporter to meet the capacity test.	INTER-DEPENDENT In order to optimize the patient's ability to best demonstrate that they meet the test for legal capacity, the patient requires the accommodation of having a decision-making supporter present to help the patient respond to the health care clinician performing the capacity assessment.	SUBSTITUTED Even with help from a decision-making supporter and other supports, the patient is unable to respond to assessment questions to meet the capacity test. The patient will require a substitute decision-maker.

Each state has unique policy on legal recognition of supporters.

[Supporteddecisionmaking.org](https://www.supporteddecisionmaking.org)

Vanderbilt Capacity Assessment Tool

ASSESS	Discuss the patient's health issue	
	ASK THE PATIENT: <i>Can you tell me or show me what is bothering you? Will you let me try to help you feel better? Or: Can you tell me why it is important for you to keep from getting sick?</i>	
▶ INFO or ke unde ques	The patient is able to and does understand his or her health issue	☐ Yes ☐ No ☐ Unsure
▶ TIPS repe	Discuss the proposed treatment	
▶ IF YC	Describe or show what you and your patient would have to do in the proposed treatment.	
▶ IF YC some help	ASK THE PATIENT: <i>Can you tell me or show me what I am asking you to do?</i>	
▶ IF YC or re you	The patient is able to understand and does understand what the proposed treatment involves	☐ Yes ☐ No ☐ Unsure
Accor	Discuss the treatment benefits for the patient's health	
Accor inputs appoi allowi skills patie occupational therapist).		g r this gist,

Supported Decision-Making vs Guardianship

	Guardianship	Supported Decision-Making
Who makes the decision?	The guardian has the rights to make the final decision about the ward's life.	The person with a disability uses support, but ultimately makes the final choice about his own life.
What decisions are made?	Medical AND/OR Financial Individual cannot vote, marry, or manage money in some cases.	Varies based on supported-decision making agreement.
What is the role of the court?	All changes go through the court. If a guardian dies, the court must approve any changes.	The person with the disability can change the supporters without a court process.
How are the person's support needs assessed?	The judge evaluates a person's needs based on a person's IQ score, diagnosis, etc, and ADL/iADL support needs.	The strengths and needs are discussed by a person and the supporters. These can be modified over time.

Find your state of practice's laws.



NOT all adults with intellectual disability need Guardianship.

Mentation Assessment in Spina Bifida

☐ Cognitive Function

- Screen with a validated tool

☐ Delirium

- Knowing baseline is key
- Shunt Assessment

☐ Depression & Anxiety

- Screen alone when possible

☐ Decision Making Capacity Assessment

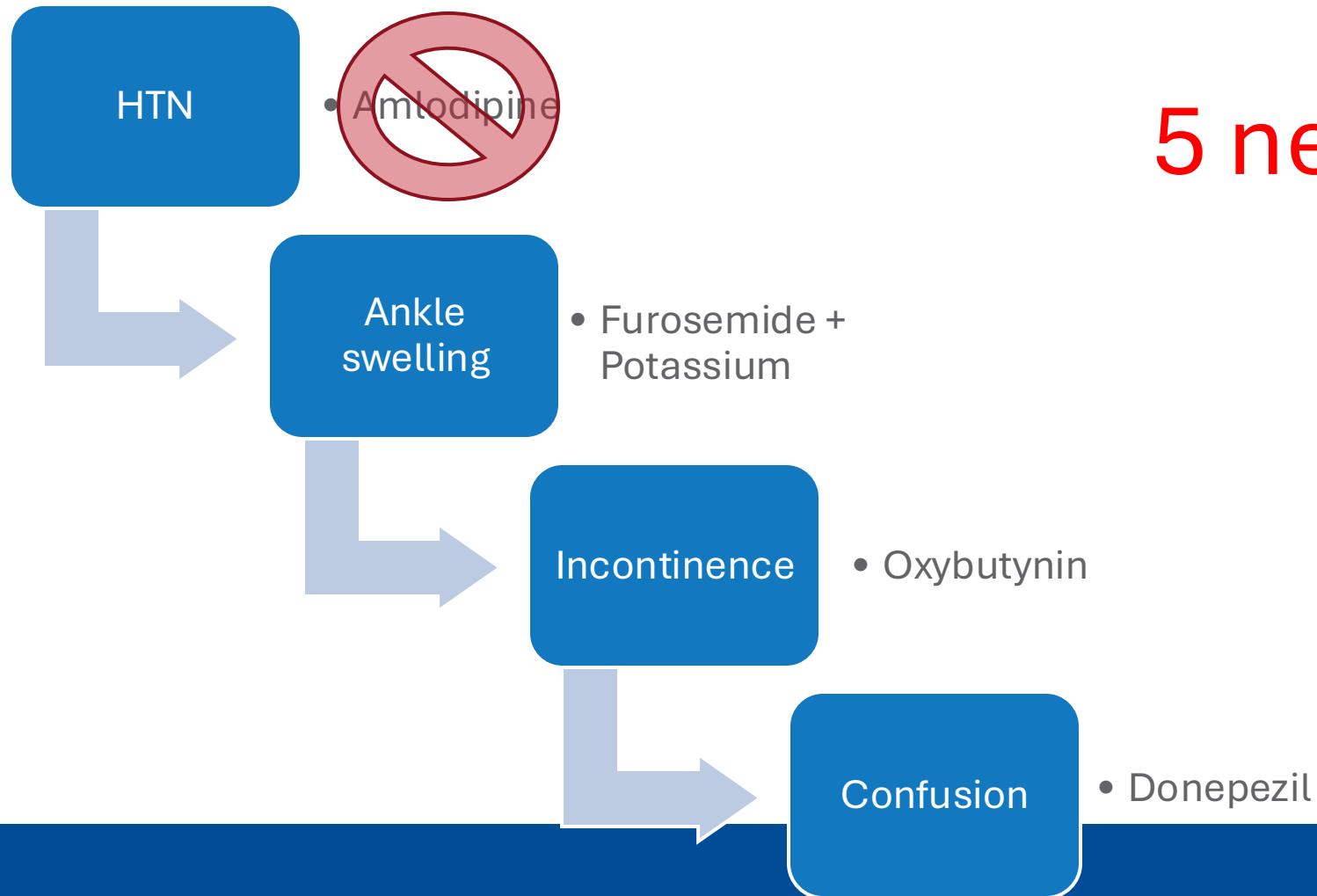
Medications



Polypharmacy

- Old definition:
 - “If a patient is taking 5 or more medications”
- New definition:
 - Focus on inappropriateness:
 - Use of one medication to treat side effects of another
 - On medications that are not clinically indicated
 - Unnecessary pill burden
 - Three times a day versus daily
 - Beers Criteria

Polypharmacy Cascade



5 new pills!



Approach to Assessing Medication

- ☐ DO the medication reconciliation!

 - ☐ *family, pharmacy, controlled substance website*

- ☐ Medication Management Hx

 - ☐ Who manages meds? Is the frequency feasible? Meds affordable?

 - ☐ Instructions clear and written down? Does the patient understand why?

- ☐ Are there side effects?

 - ☐ Avoid deliriogenic medications – use tools like **Beers Criteria**

 - ☐ Is the risk-benefit appropriate

- ☐ Always consider meds on your differential diagnosis for a problem

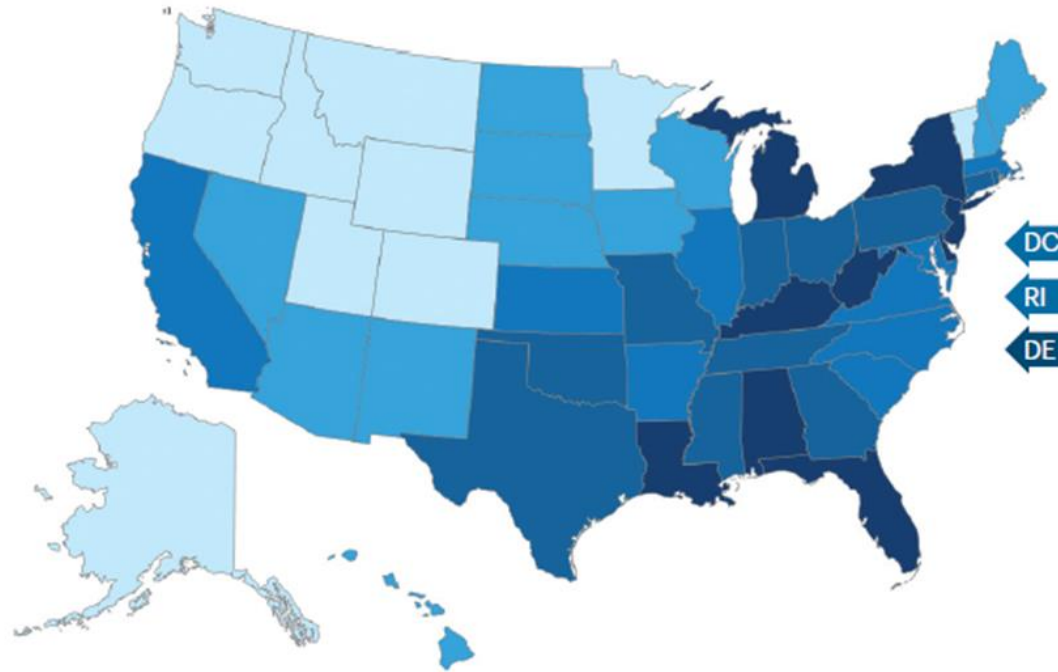
Multicomplexity



Multiple Chronic Conditions

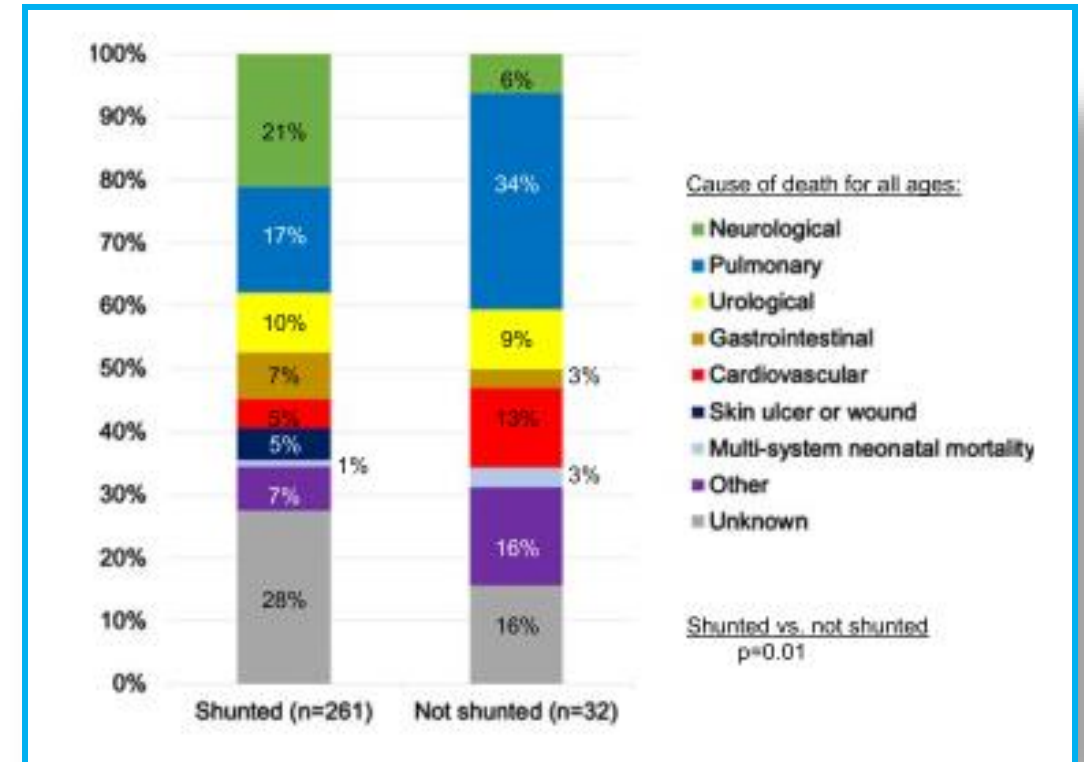
Percentage of Medicare enrollees aged 65 years and older with four or more chronic conditions

≤28.7% 28.8% to 33.6% 33.7% to 38.3% 38.4% to 40.5% ≥40.6%



Multicomplexity in Spina Bifida

- SB impacts **multiple organ systems**.
- When evaluating mechanisms of death, **infections, pulmonary failure, and cardiovascular disease** was most cited on death certificates.
- Skin Ulcers, Respiratory support, Obesity, CKD, HTN, depression common in the last year of life.



53 year old with lumbar MMC and HC with VP shunt, neurogenic bladder on CIC presents for his annual visit. His blood pressure is **155/95**.

Does the patient have an average BP $\geq 140/90$ mm Hg?



Initiate antihypertensive medications to lower BP and reduce CVD risk for primary or secondary prevention of CVD

1

Cardiovascular Risk Assessment

Lipid Profile to Calculate PREVENT Score

A1C

BMI & Dietary H/x

Renal Assessment

Annual US and Cr

Review CIC Patterns

OSA Evaluation

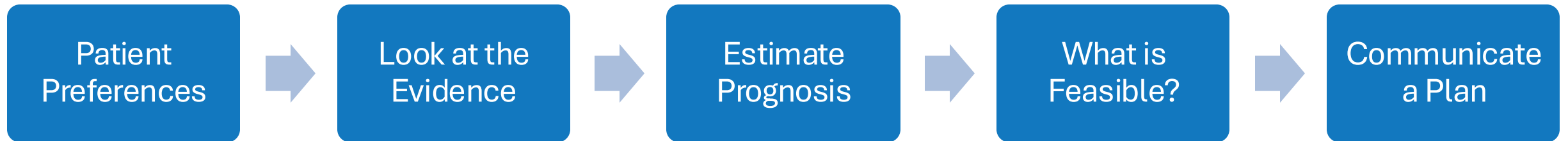
STOP BANG

Sleep Medicine Referral

Pain Assessment

Chronic and Acute

Approach to Older Adults with Multimorbidity



Multicomplexity - Assessment

- ☐ **Optimization of comorbidities**

- ☐ Metabolic and cardiovascular diseases guideline-directed care
- ☐ Sexual Health & Menopause Care
- ☐ Neurogenic Bowel & Bladder Management

- ☐ **Evaluate overall prognosis.**

- ☐ **Apply preventative screening guidelines.**

- ☐ Reference SB Guidelines.



What Matters Most



What Matters Most: Goals of Care

■ Assessing Priorities

- Tell me about yourself and your family.
- What is most important to you?
- What is worrying you the most?
- If time was limited, how would you want to spend it?

■ Assessing Expectations

- Does the evaluation/treatment align with goals?
- Is surgery/treatment what the patient is wanting or expecting?
- Is the patient prepared for expected recovery?

What Matters Most: Community & Connection

Texas Workforce Commission

Table 3. Respondent perception of the impact of spina bifida on adult milestones

Adult milestones		
Having spina bifida affects my:	Sometimes or always feel this way	
	<i>n</i>	%
Ability to participate in the community	38	53%
Ability to go to college	18	25%
Choices in having children	39	54%
Plans for the future	40	56%
Personal relationships (dating, marriage, close friendships)	40	56%
Ability to work (employment)	37	51%
Independence	35	49%
Options of where I can live	36	50%
Transportation options (car, bus)	37	51%



Join the Adult Facebook Group Here

SAMPLE LANGUAGE FOR ACCOMMODATION
REQUEST LETTERS

Adaptive Driving Program

What Matters Most: Advance Directives

- ☐ Medical Power of Attorney
- ☐ Code status
- ☐ Advanced Directives
- ☐ Community Engagement & Connection

Summary

- Cognitive changes, frailty, polypharmacy, and multicomplexity can make care of older adults challenging with and without Spina Bifida.
- Think about the 5Ms when organizing care of older adults with Spina Bifida.



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