



PALLIATIVE CARE FOR PERSONS WITH DEMENTIA

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MILD

MODERATE

SEVERE

TERMINAL

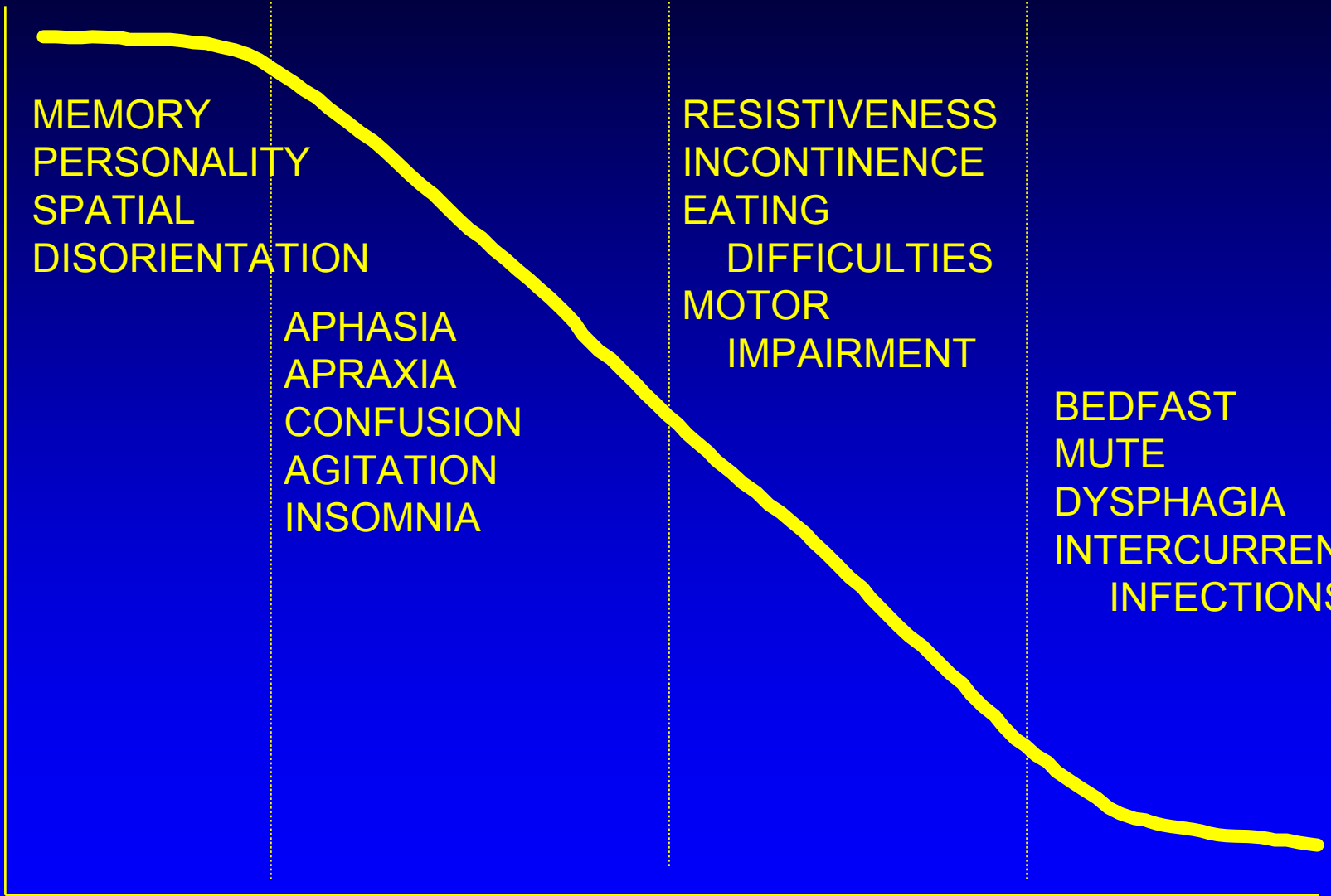
MEMORY
PERSONALITY
SPATIAL
DISORIENTATION

APHASIA
APRAXIA
CONFUSION
AGITATION
INSOMNIA

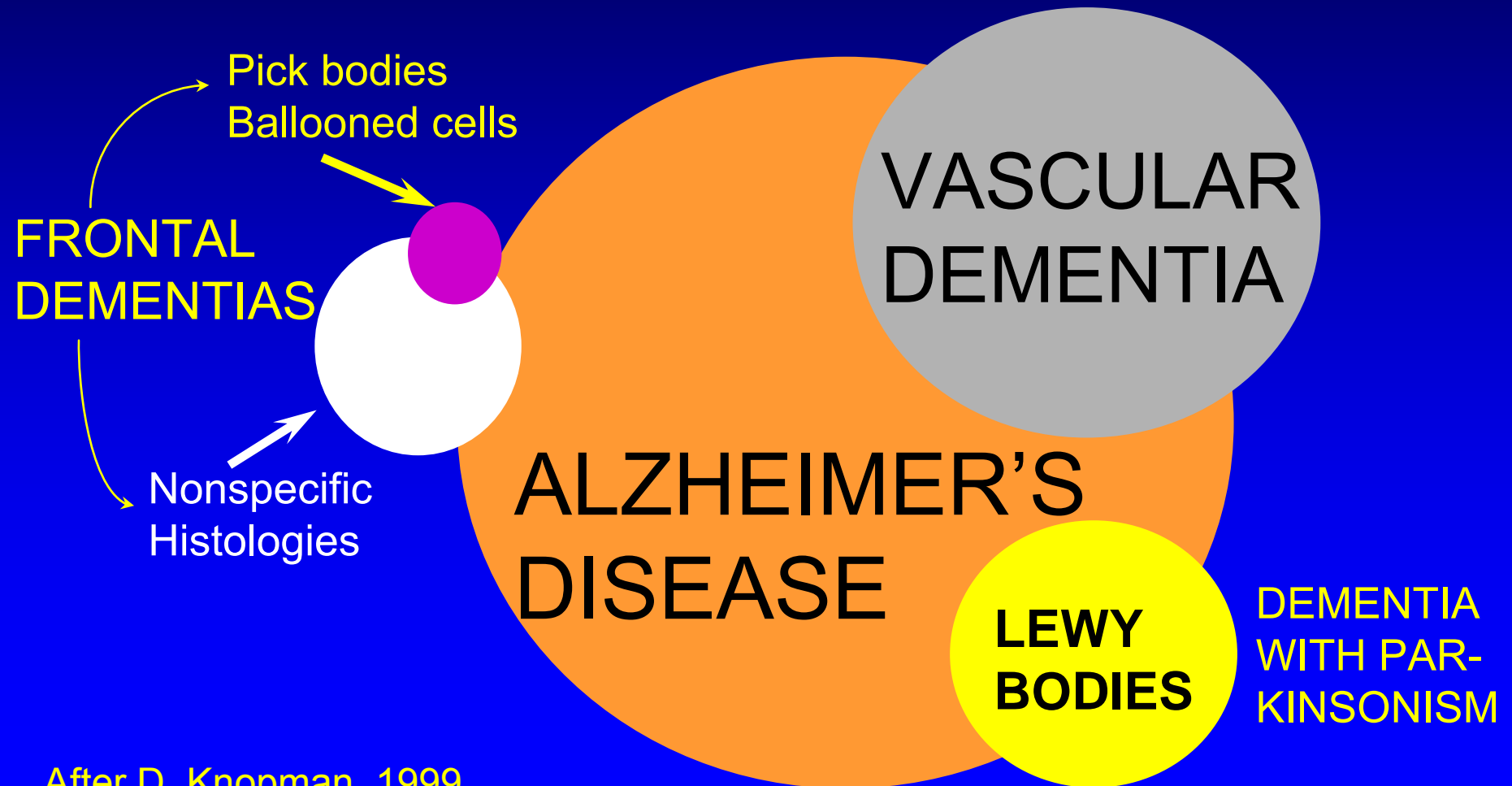
RESISTIVENESS
INCONTINENCE
EATING
DIFFICULTIES
MOTOR
IMPAIRMENT

BEDFAST
MUTE
DYSPHAGIA
INTERCURRENT
INFECTIONS

TIME

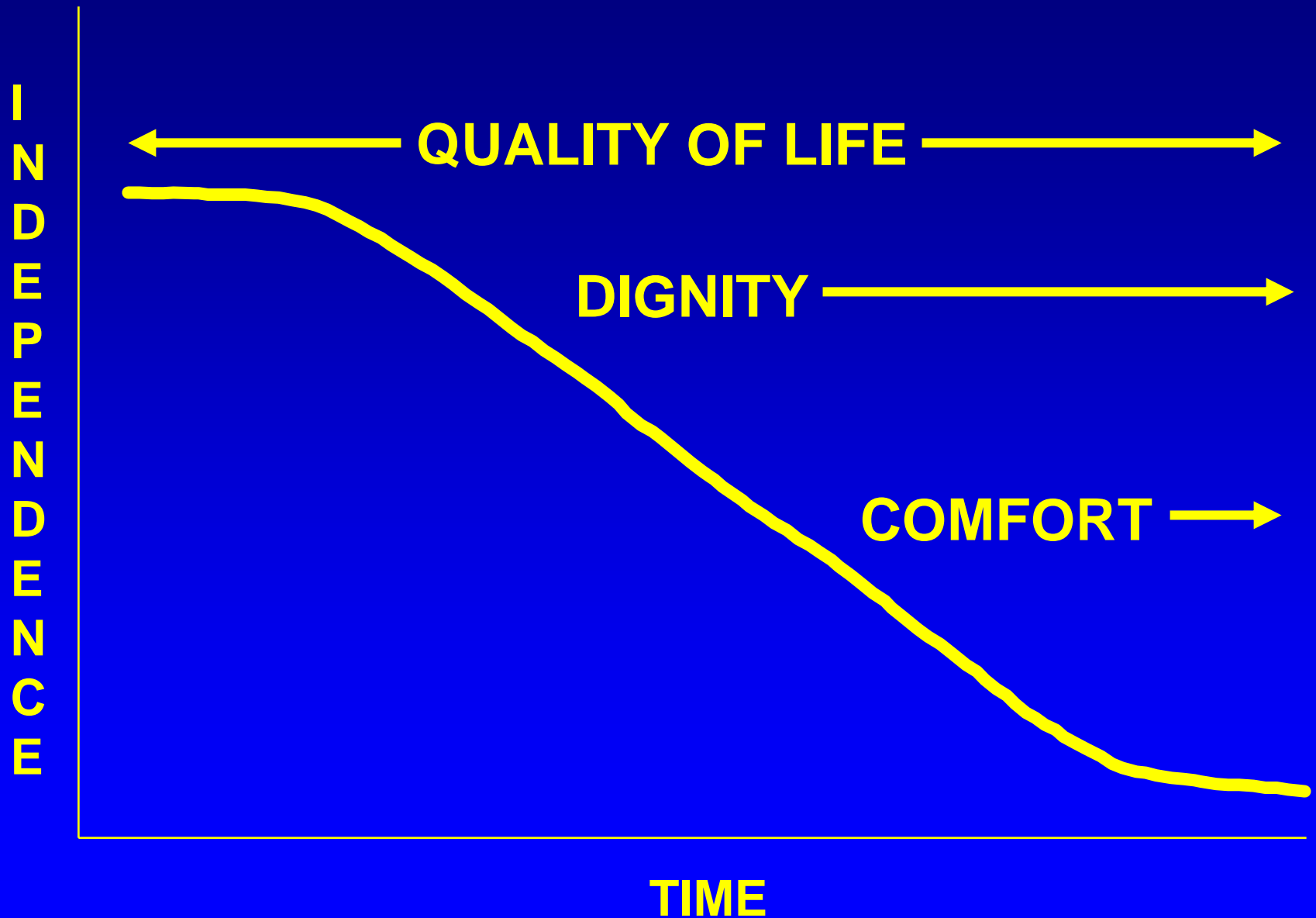


PROGRESSIVE DEMENTIAS



After D. Knopman, 1999

GOALS OF DEMENTIA CARE



**MEANINGFUL
ACTIVITIES**

A Venn diagram with three overlapping circles on a blue background. The top circle is yellow and labeled 'MEANINGFUL ACTIVITIES'. The bottom-left circle is green and labeled 'MEDICAL ISSUES'. The bottom-right circle is white and labeled 'PSYCHIATRIC SYMPTOMS'. The intersection of the top and bottom-left circles is labeled 'MOTOR ACTIVITY'. The intersection of the top and bottom-right circles is labeled 'DEPRESSION'. The intersection of the bottom-left and bottom-right circles is labeled 'COMFORT'. The central intersection of all three circles is shaded pink and labeled 'QOL'.

**MOTOR
ACTIVITY**

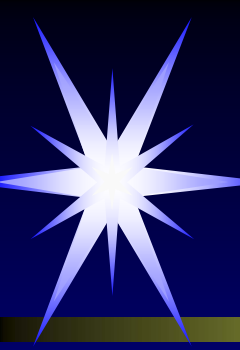
**DEPRES-
SION**

QOL

**MEDICAL
ISSUES**

**COM-
FORT**

**PSYCHIATRIC
SYMPTOMS**



MEANINGFUL ACTIVITIES

➤ ACTIVITIES OF DAILY LIVING (ADLs)

- Appropriate level of cueing, set up and assistance, controlled choices, routine

➤ PHYSICAL ACTIVITIES

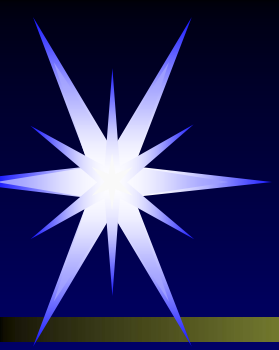
- Improve mood, strength, sleep, tone

➤ COGNITIVE ACTIVITIES

- Games, sorting, brain exercises, reminiscence

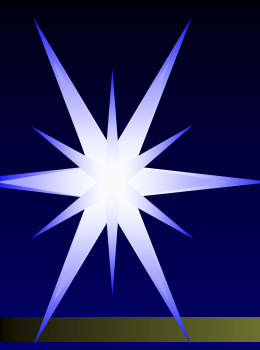
➤ CREATIVE ACTIVITIES

- Drawing, singing, crafts, dance, music



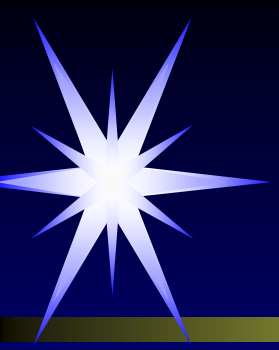
SPECIAL PROGRAMS

- **INDIVIDUALIZATION OF CARE**
 - Individual music, Lifestyle approach
- **PROMOTION OF FUNCTIONAL INDEPENDENCE**
 - Minimal dressing assistance, exercise
- **USE OF TECHNOLOGY**
 - Simulated Presence Therapy, Snoezelen
- **ALTERNATIVE THERAPIES**
 - Music, reminiscence, pet therapy



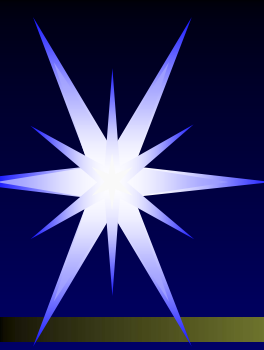
CONTINUOUS ACTIVITIES

- Activity programming or presence of others most of their waking hours
- Residents with all stages of dementia
 - Adjusted to dementia severity
 - Planned and unplanned activities
 - Involvement of all staff, family and volunteers



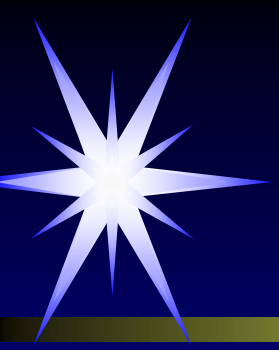
IMPACT OF THE CLUB

Variable	Before	After	X ² (t)	p
Psychoactive medications	20	8	10.3	<.01
Weight: loss	9	1	14.7	<.001
gain	1	11		
Social isolation	15	5	7.8	<.01



PVS IN ALZHEIMER'S DISEASE

- 12 patients unable to eat independently, respond to command, walk, incontinent
- 9.4 years history, 43 months institutionalization
- No agreement among three neurologists on any patient



QUALITY OF LIFE CONSIDERATIONS

- Patients almost never reach a persistent vegetative state
 - **Need for sensory stimulation (Namaste)**
- Optimal medical interventions
 - **Establish goals of care**
- Management of behavioral symptoms
 - **Treat / eliminate depression**

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**MOTOR
ACTIVITY**

**DEPRES-
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QOL

**MEDICAL
ISSUES**

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**PSYCHIATRIC
SYMPTOMS**



WALKING DIFFICULTIES IN ALZHEIMER'S DISEASE (AD)

LACK OF VISUAL RECOGNITION OF OBSTACLES

NEUROMOTOR CHANGES

UNSTEADY GAIT/SCISSORING

RISK FOR FALLS

IMMOBILITY

DECONDITIONING

CONTRACTURES

50% OF AD PATIENTS LOOSE THE ABILITY TO WALK INDEPENDENTLY 7.8 YEARS AFTER ONSET OF AD

USE OF MERRY WALKER IN ALZHEIMER'S DISEASE

- **IMPROVED MOBILITY**
- **DECREASED DAY TIME SLEEP**
- **IMPROVED MOOD**
- **INCREASED ENGAGEMENT**
- **NO INJURIES**



DECREASED MOBILITY

➤ BEDFAST STATUS

➤ UTI (OR = 3.4)

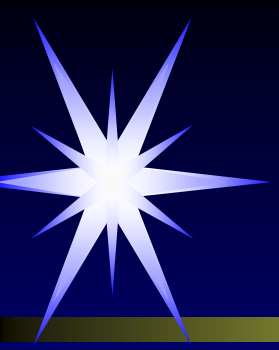
➤ PNEUMONIA (OR=6.6)

➤ PRESSURE ULCERS



FACTORS AFFECTING MANAGEMENT STRATEGIES

- REDUCED LIFE EXPECTANCY
- INDUCTION OF DISCOMFORT
- INABILITY TO REPORT
SYMPTOMS

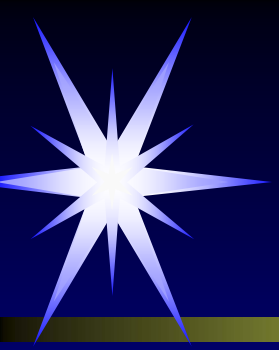


MEDICAL ISSUES

INTERCURRENT INFECTIONS

ASPIRATION

EATING DIFFICULTIES



MEDICAL INTERVENTIONS

- **CPR - < 2% DISCHARGED ALIVE**
(Applebaum et al., JAGS 38, 197, 1990)
- **TRANSFER TO A HOSPITAL**
 - **HIGHER MORTALITY AT TWO MONTHS THAN THOSE TREATED AT NH** (Fried et al., JAGS 45, 302, 1997)
 - **>50% MORTALITY RATE AT 6 MONTHS AFTER HOSPITALIZATION FOR PNEUMONIA OR HIP FRACTURE**
(Morrison and Siu, JAMA 284,47,2000)

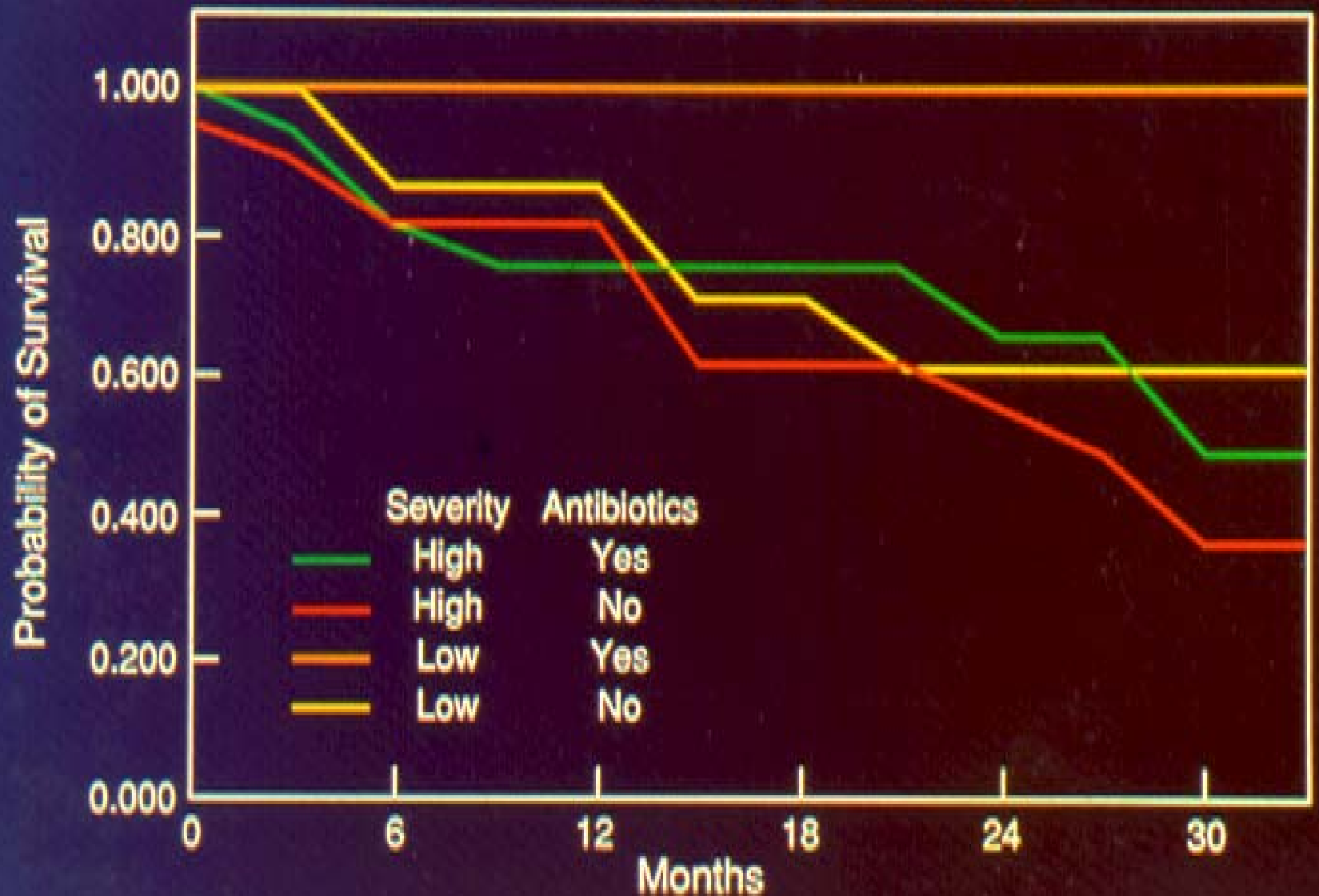
FACTORS CONTRIBUTING TO DEVELOPMENT OF INTERCURRENT INFECTIONS

- CHANGES IN IMMUNE FUNCTION
- DIFFICULTIES IN DIAGNOSING INFECTIONS
- INCONTINENCE
- DECREASED MOBILITY
- ASPIRATION

ASPIRATION

- FOOD AND LIQUIDS
- PHARYNGEAL SECRETIONS
 - DURING SLEEP
 - 45% OF HEALTHY SUBJECTS
 - 70% IN DEPRESSED CONSCIOUSNESS
- STOMACH CONTENT
 - COLONIZATION AFTER INHIBITION OF GASTRIC ACID SECRETION

ANTIBIOTICS AND FEVER IN ALZHEIMER'S DISEASE



DISCOMFORT SCALE

NOISY BREATHING

NEGATIVE VOCALIZATION

CONTENT FACIAL EXPRESSION

SAD FACIAL EXPRESSION

FRIGHTENED FACIAL EXPRESSION

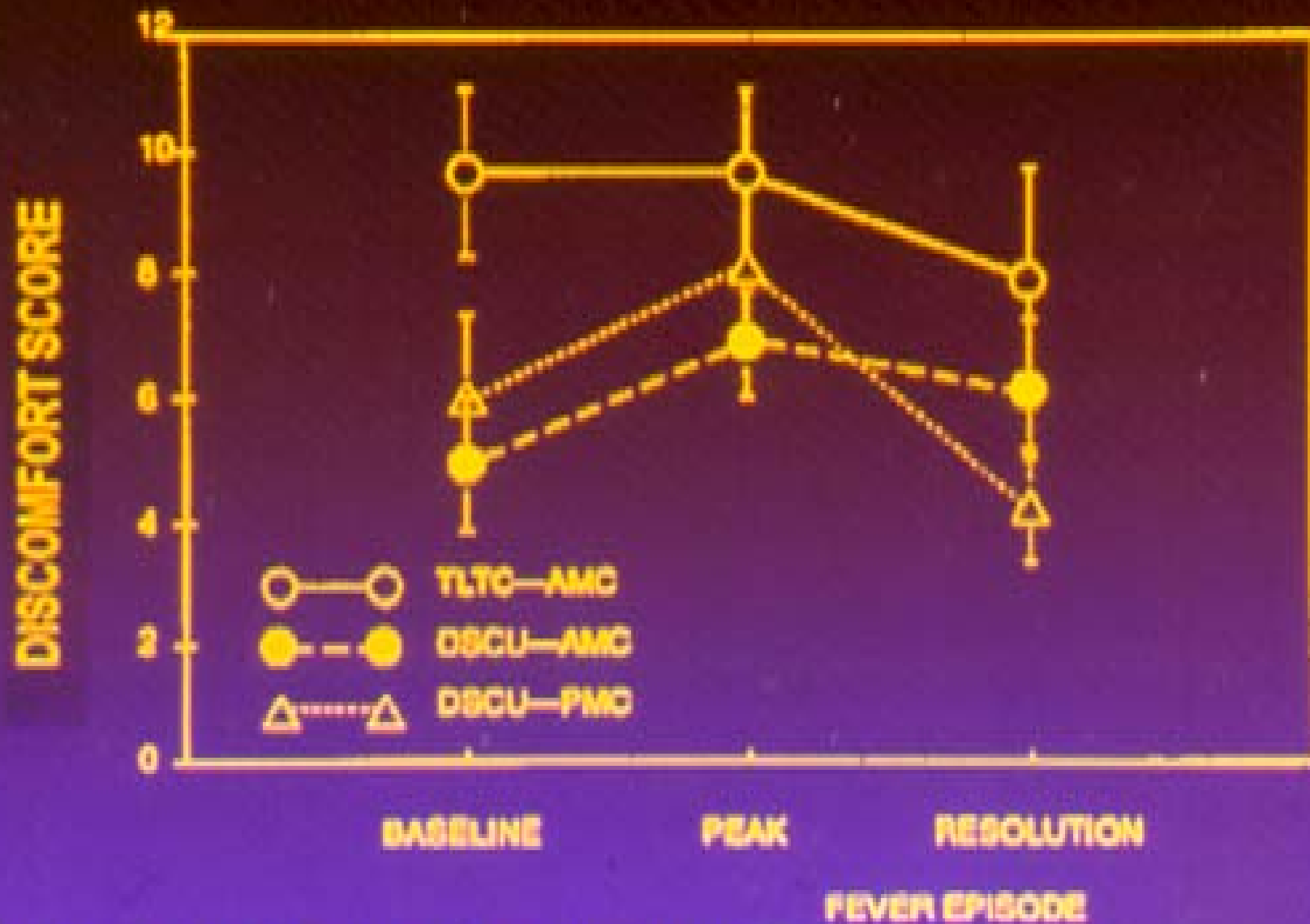
FROWN

RELAXED BODY LANGUAGE

TENSE BODY LANGUAGE

FIDGETING

DISCOMFORT DURING A FEVER EPISODE



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MODERATE

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TERMINAL

WEIGHT
LOSS

APRAXIA

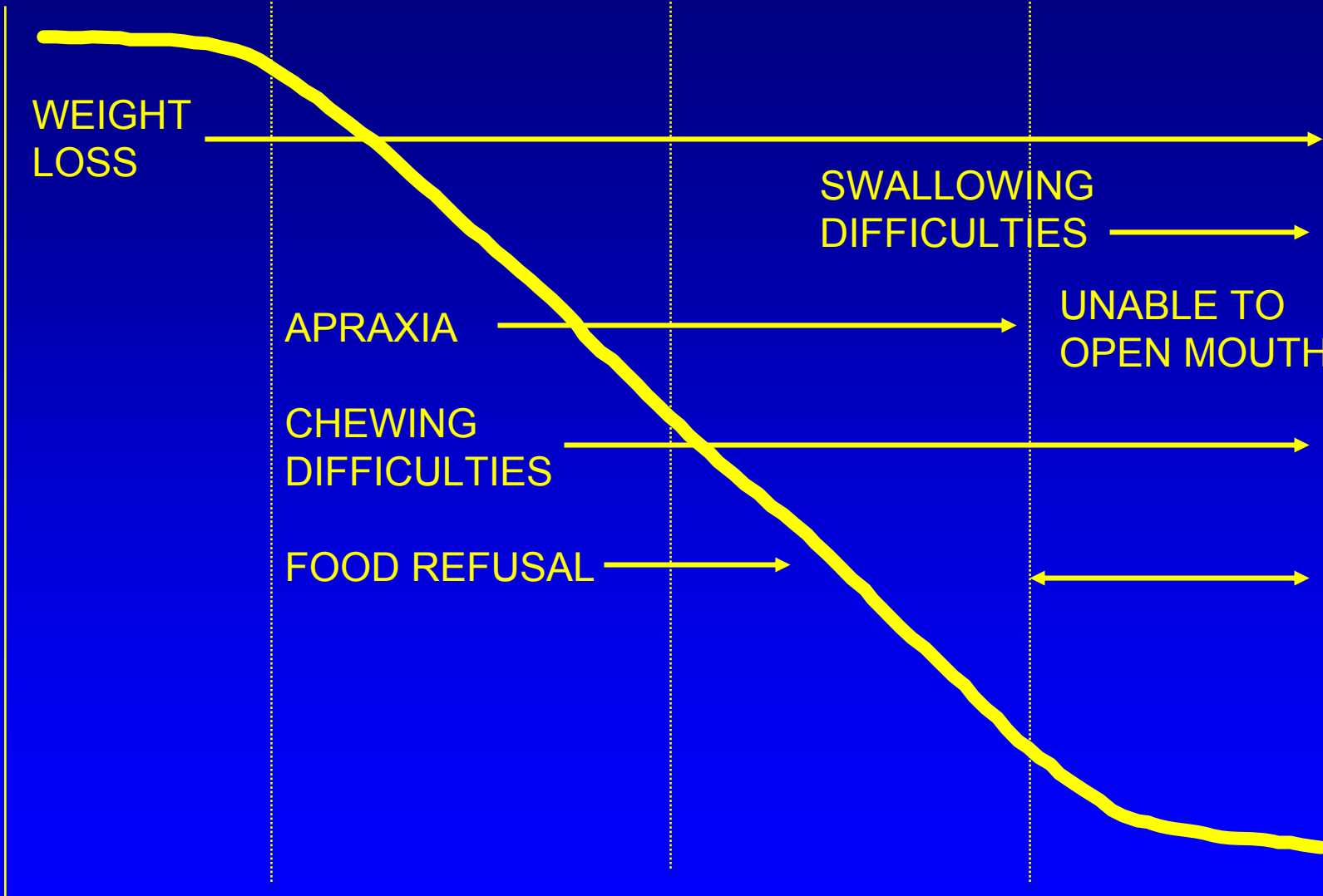
CHEWING
DIFFICULTIES

FOOD REFUSAL

SWALLOWING
DIFFICULTIES

UNABLE TO
OPEN MOUTH

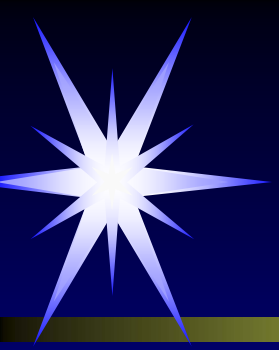
PROGRESSION OF DEMENTIA





TREATABLE CAUSES OF WEIGHT LOSS

- FEVER, INFECTION
- INCREASED ENERGY USE (PACING)
- DEPRESSION
- MEDICATIONS
- COPD, END-STAGE
- RESTRICTIVE DIETS
- THYROID DISEASE
- CANCER

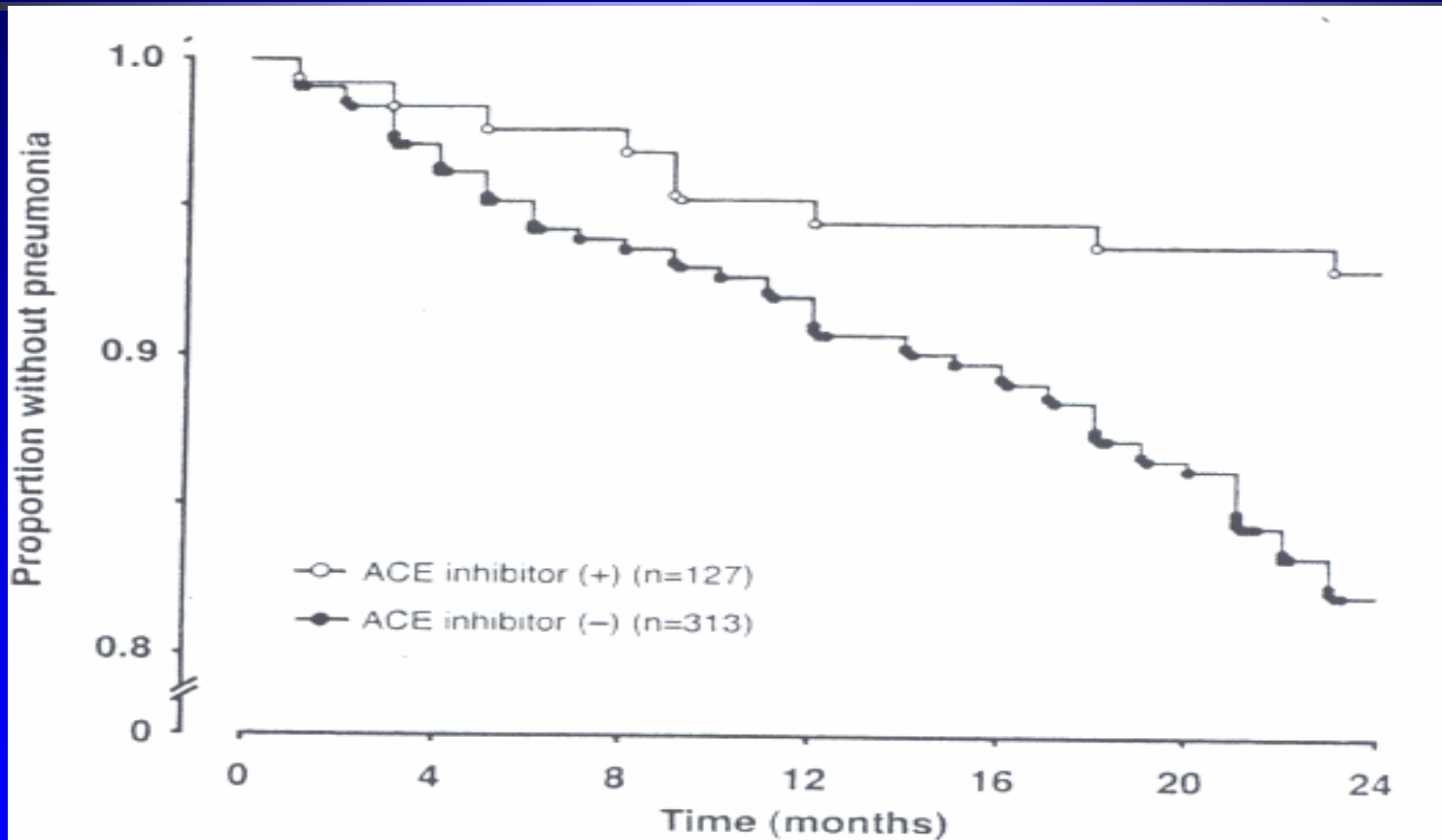


MANAGEMENT OF FOOD REFUSAL

- ANTIDEPRESSANT TREATMENT
 - MOOD IMPROVEMENT
 - SERTRALINE (ZOLOFT)

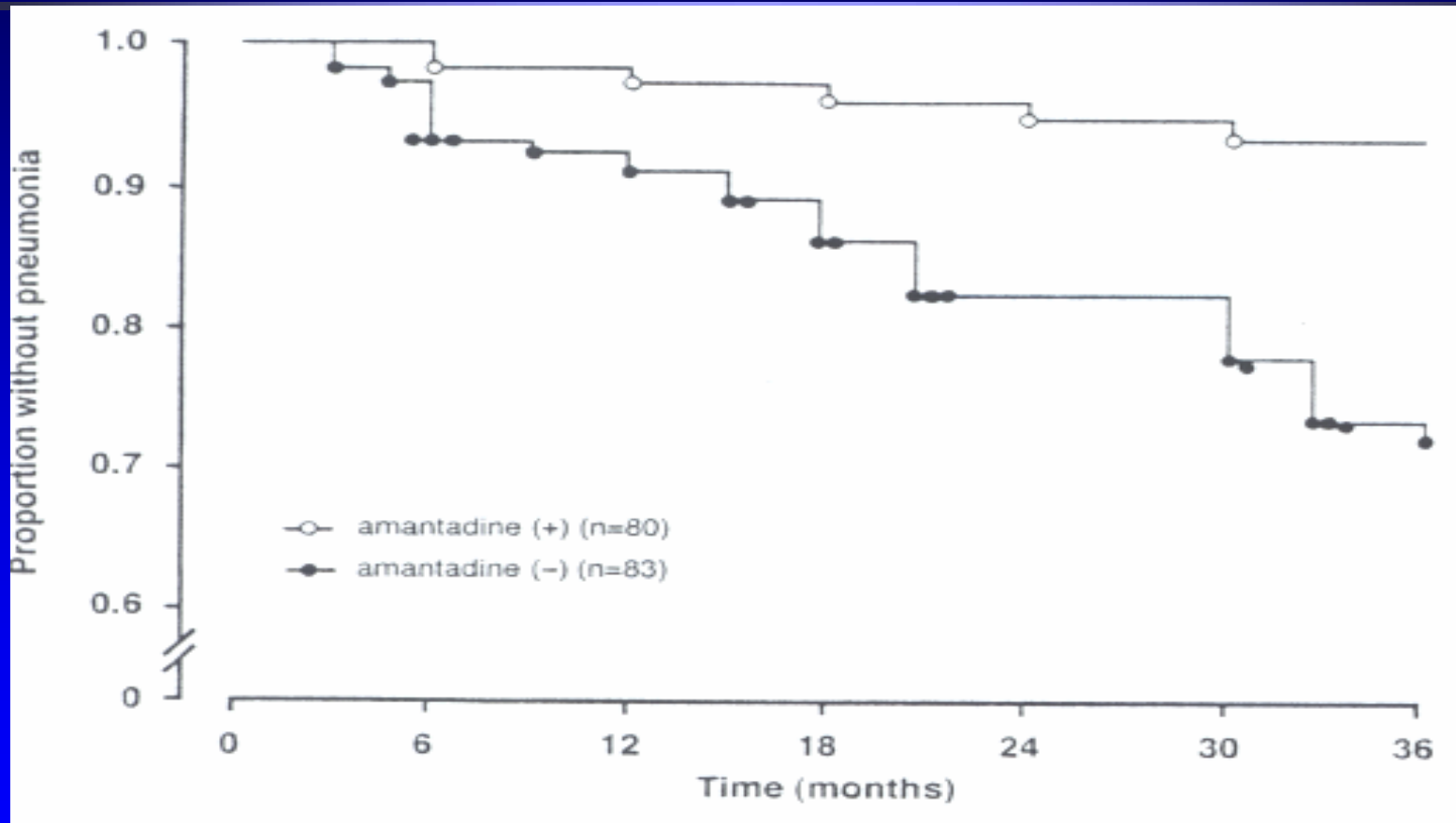
- DRONABINOL (MARINOL)
 - ALSO IMPROVEMENT OF DISTURBED BEHAVIOR

PREVENTION OF ASPIRATION PNEUMONIA BY ACE INHIBITORS

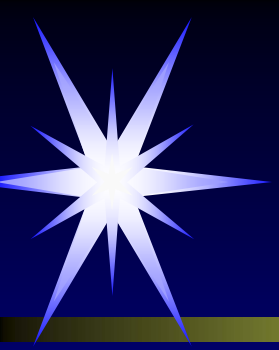


Sekizawa et al. Lancet 352:1069, 1998

PREVENTION OF ASPIRATION PNEUMONIA BY AMANTADINE



Nakagawa et al. Lancet 353:1157, 1999



MULTIVARIATE ANALYSIS OF RISK FACTOR FOR ASPIRATION

RISK FACTOR	P	OR	95% CI
DYSPHAGIA	.173	1.8	0.8- 4.1
HYPEREXTENDED NECK	.006	4.0	1.5-10.7
MALNUTRITION	.047	2.2	1.0- 4.7
BENZODIAZEPINES	<.001	3.8	1.8- 8.2
CONTRACTURES	.006	3.2	1.4- 7.3
TUBE FED	.008	3.0	1.3- 6.6

(Pick et al., JAGS 44:766,1996)

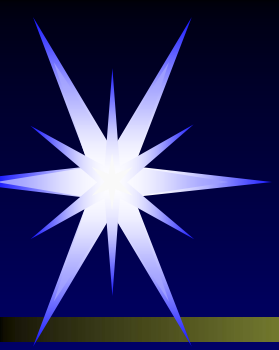


MEAN DISCOMFORT RATING (1-10)

(n=100)

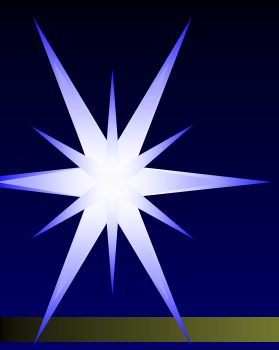
Nasogastric tube	8.8 _± 1.9
Mechanical ventilation	8.0 _± 5.4
Mechanical restraints	7.8 _± 3.2
Indwelling urethral catheter	6.2 _± 2.9
Phlebotomy	3.6 _± 2.6
I.M. or S.C. injection	3.5 _± 2.7
Movement from bed to chair	2.6 _± 2.6

Morrison et al. J.Pain Sympt.Manag.15,91,1998



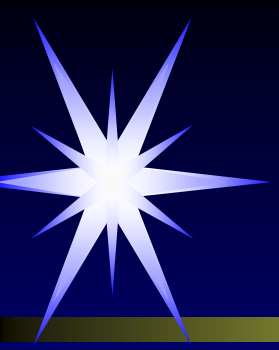
DISADVANTAGES OF TUBE FEEDING

- **DISCOMFORT, RESTRAINTS**
- **LACK OF TASTE OF FOOD**
- **LACK OF CONTACT WITH CAREGIVERS**
- **COMPLICATIONS**
 - DIARRRHEA AND CRAMPS**
 - NAUSEA, VOMITING, ABDOMINAL DISTENTION**
 - TUBAL OBSTRUCTION AND MIGRATION**
 - INFECTION AND LEAKAGE OF STOMA**



PREVENTION OF TUBE FEEDING

- PALLIATIVE PHILOSOPHY OF CARE
- EARLY DISCUSSION OF ADVANCE DIRECTIVES
- CONTINUOUS EFFORT TO FEED PATIENTS BY NATURAL MEANS
- MAINTAINING QUALITY OF LIFE
- CONTINUOUS COMMUNICATION WITH PATIENTS FAMILIES



DISCONTINUATION OF TUBE FEEDING

CHARACTERISTICS	PATIENT				
	1	2	3	4	5
AGE	64	79	76	69	69
DURATION OF DAT (years)	4	9	6	5	5
DURATION OF TUBE FEEDING (days)	365	30	15	43	10
Mini-Mental State Score	7	0	3	0	0
LANGUAGE ASSESSMENT	14	8	13	8	4
DURATION OF SURVIVAL (months)	10	45	15	4	35

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MOTOR
ACTIVITY

DEPRES-
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QOL

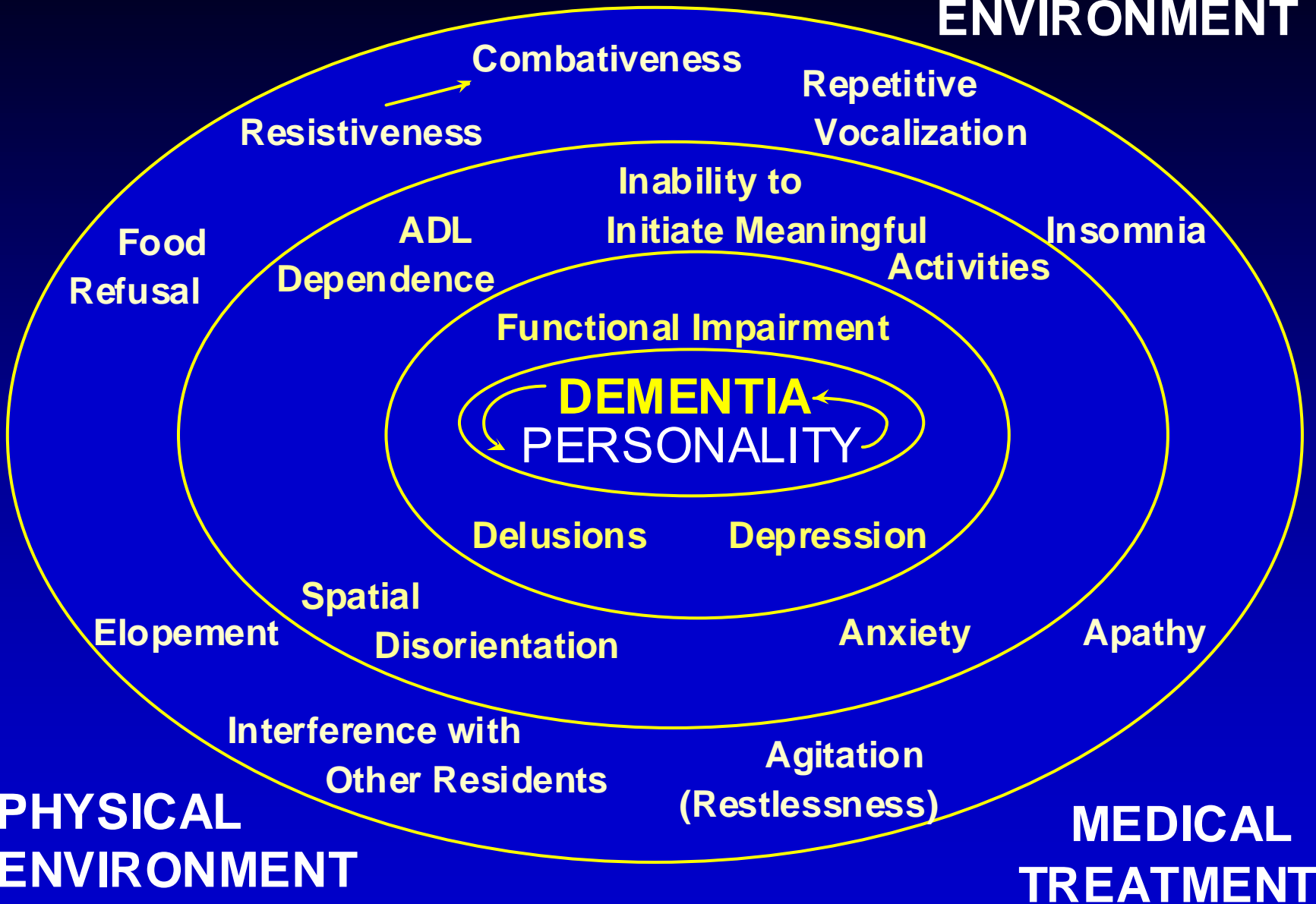
**MEDICAL
ISSUES**

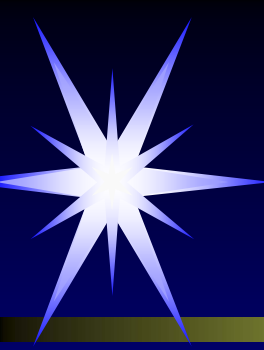
COM-
FORT

**PSYCHIATRIC
SYMPTOMS**

CAREGIVING

SOCIAL ENVIRONMENT



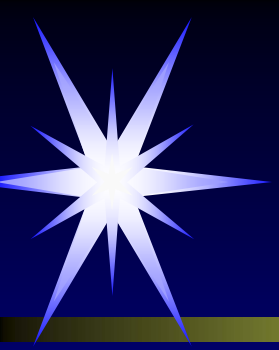


DEPRESSION IN DEMENTIA

COMMUNITY DWELLING	n(=175)	%

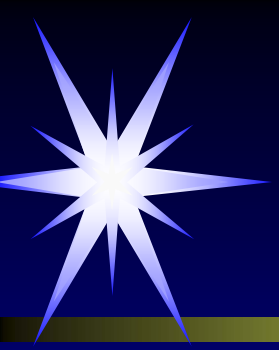
A: DYSPHORIA OR LOSS OF INTEREST	170	97.1
B: FOUR VEGETATIVE/OTHER SYMPTOMS	152	86.9
A + B	150	85.7
DISTRACTED OR CHEERED UP DURING DYSPHORIC EPISODE	135	89.8

Merriam, A.E. et al, JAGS 36:7-12,1988



RECOGNITION OF DEPRESSION IN ADVANCED DEMENTIA

- VEGETATIVE SIGNS (anorexia, insomnia)
- CHANGE IN SOCIALIZATION AND ACTIVITIES ATTENDANCE
- APATHY (isolative behavior)
- RESISTIVE BEHAVIOR DURING ADLs
- SOMATIZATION
- DELUSIONS



RECOMMENDATIONS 1

➤ CPR

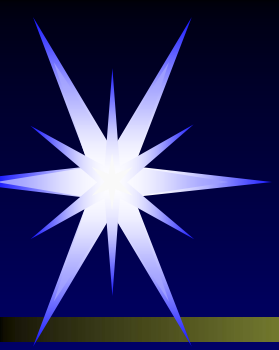
- Optional in advanced dementia
- Not performed in unwitnessed arrest

➤ Hospitalization

- Prevented by physician extenders (PACE)
- Eliminate fiscal incentives for NH

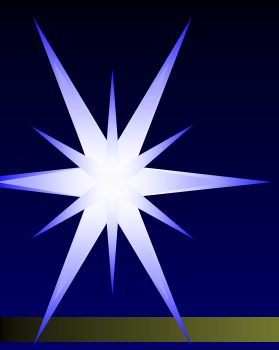
➤ Infections

- Maintain oral health
- Avoid antibiotics if comfort is goal of care



RECOMMENDATIONS 2

- Tube feeding – eliminate fiscal incentives
- End-of-life decision making
 - Increase physician involvement
 - Discuss issues other than CPR after admission
 - Provide national criteria for a surrogate
- Provide palliative care in hospice ineligible
 - Bridge program
 - Transitions
 - Palliative care program



*"People do not consist of memory alone.
They have feeling, will, sensibility, moral being.
It is here that you may touch them, and
See a profound change."*

A. Luria