

Early Onset Dementia: Screening, Diagnosing and Then What?...



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Working EOD Group

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Early Onset Dementia: Facts

- Few studies listing country prevalence
- In Japan: 42.3/100,000 (vascular 42.6%, AD (25.6%), TBI (7.1%), DLB and PD (6.2%), FTD (2.6%), others (16%)
[Stroke, 2009]

In Europe: All dementia: 38-420/100,000

AD: 15.1-153/100,000

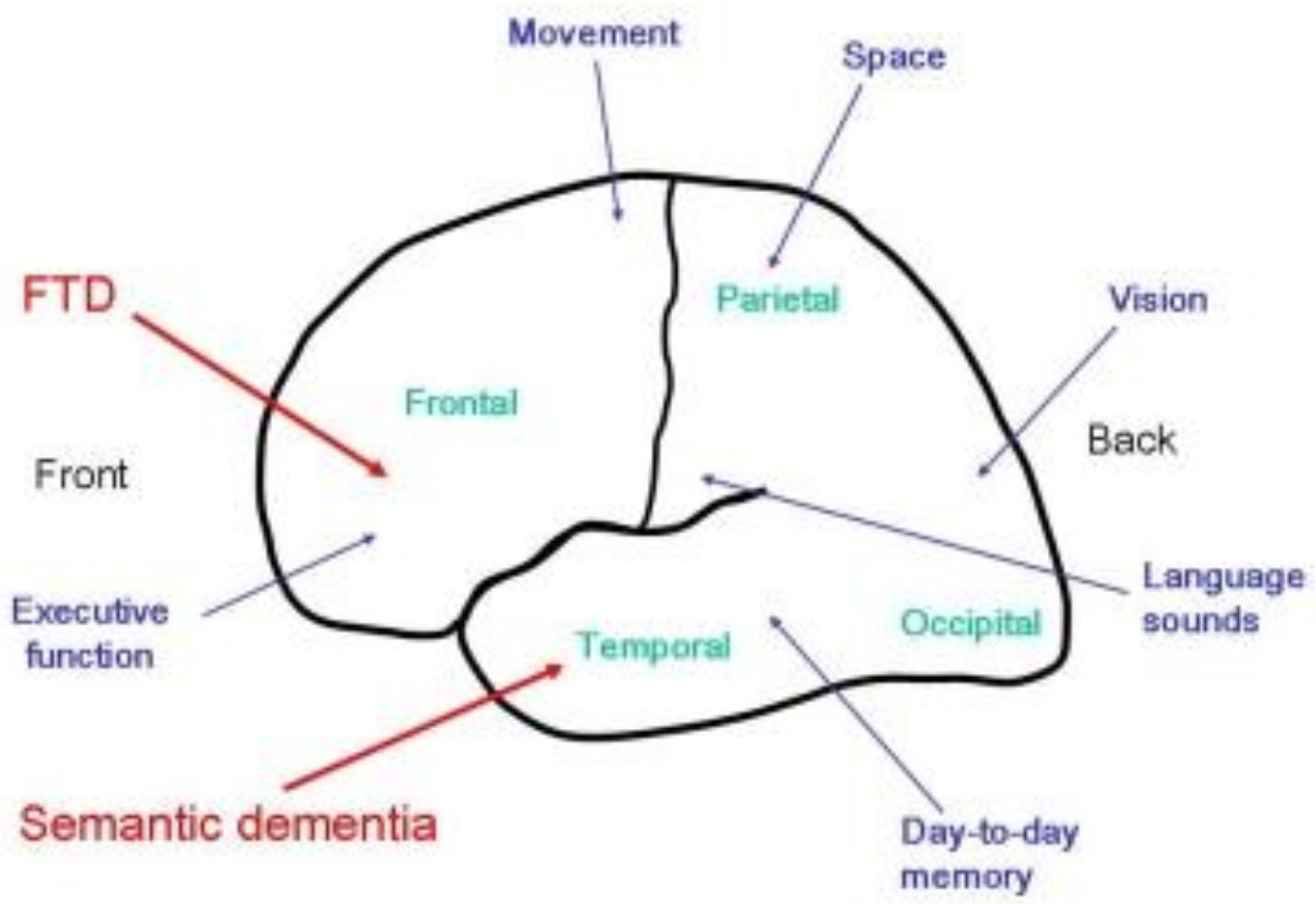
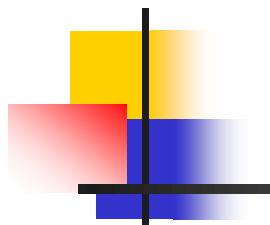
FTD : 4.0-15.4/100,000

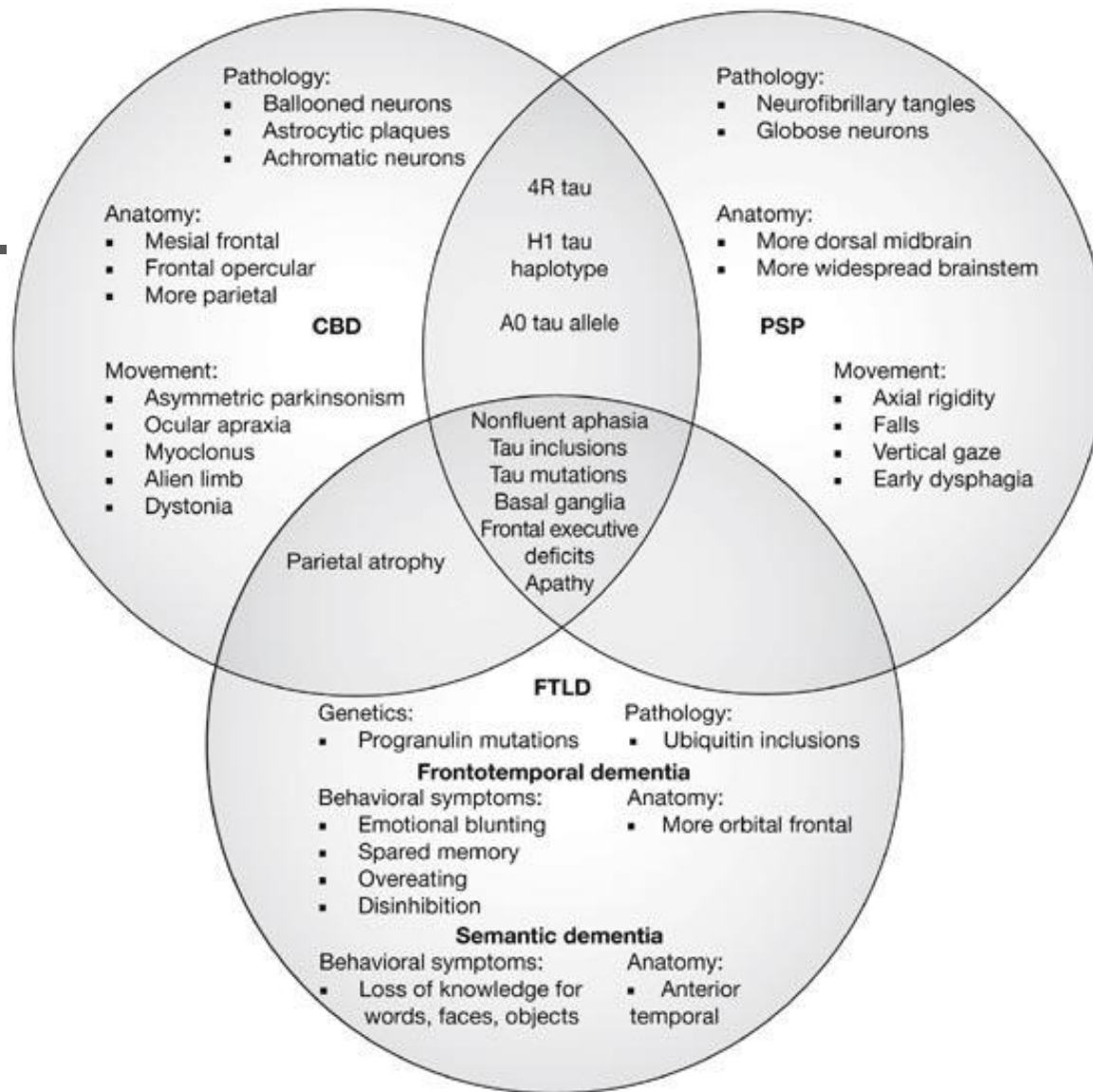
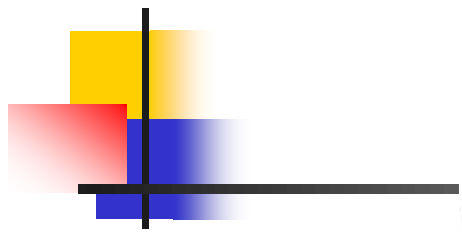
[AD Europe, 2009]



What is Fronto-Temporal Dementia?

- FTD is a group of related conditions:
- Progressive degeneration of the temporal and frontal lobes.
- Brain areas +++
decision-making
behavioral control
Emotion
language.

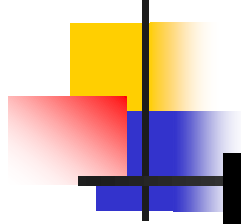
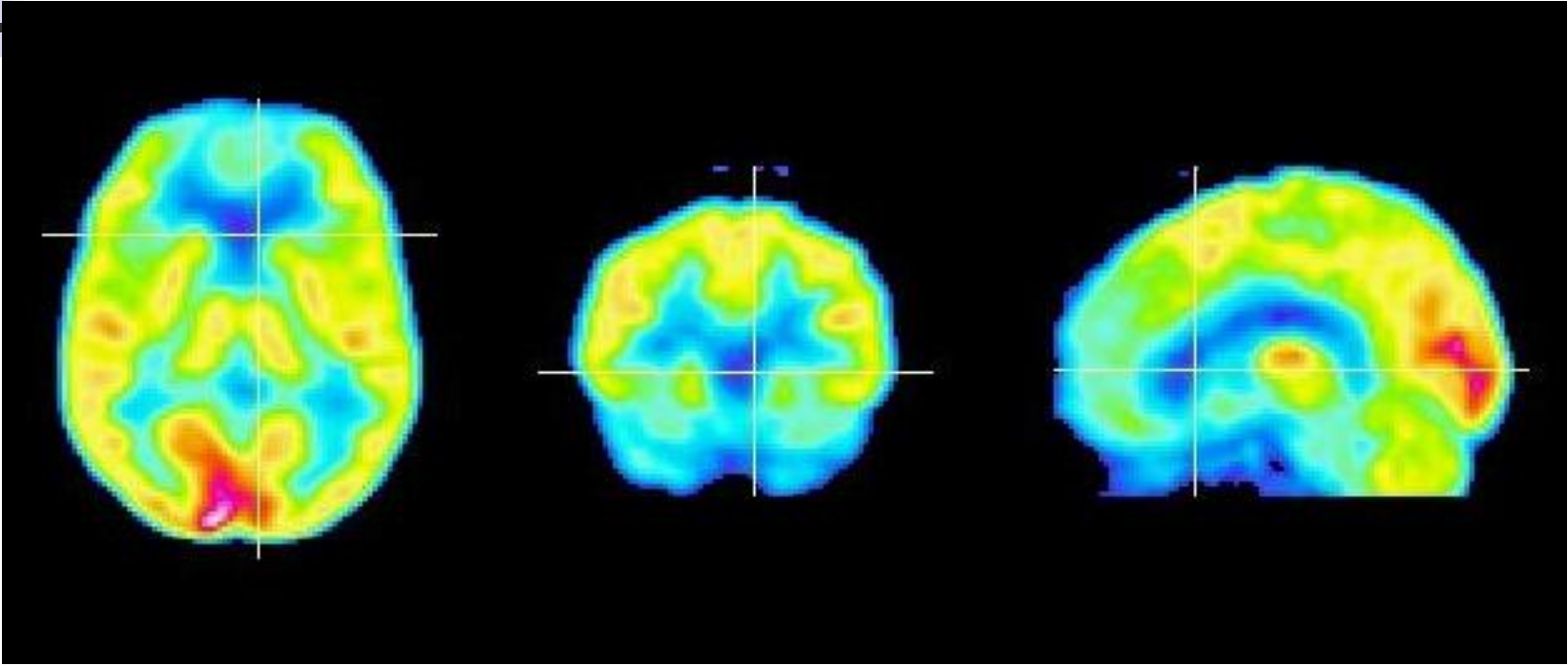


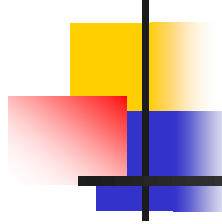
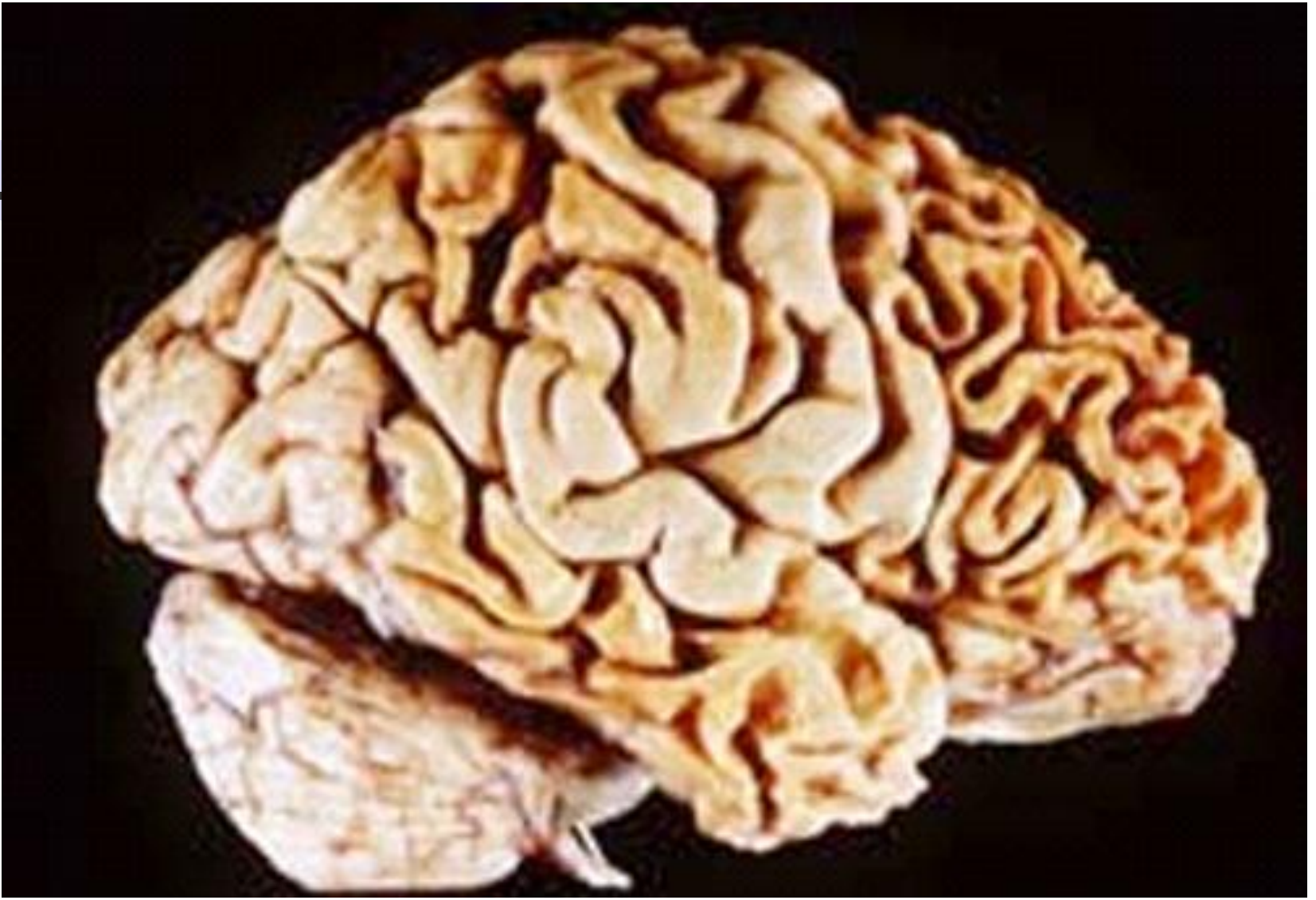




Disease Progression

- Appears mid-40s to early-60s
- Causes steady and gradual decline
- Can last from 3-17 years from the first symptom until death
- Average duration of eight years after diagnosis







Early Onset Dementia: The Challenges

- Difficult diagnosis to make and carry
- Family issues: kids, young partnership
- Impact on employment
- Impact on finances
- Impact on ancillary services offered
- Impact on quality of life



Charts Data Review (2005-2008)

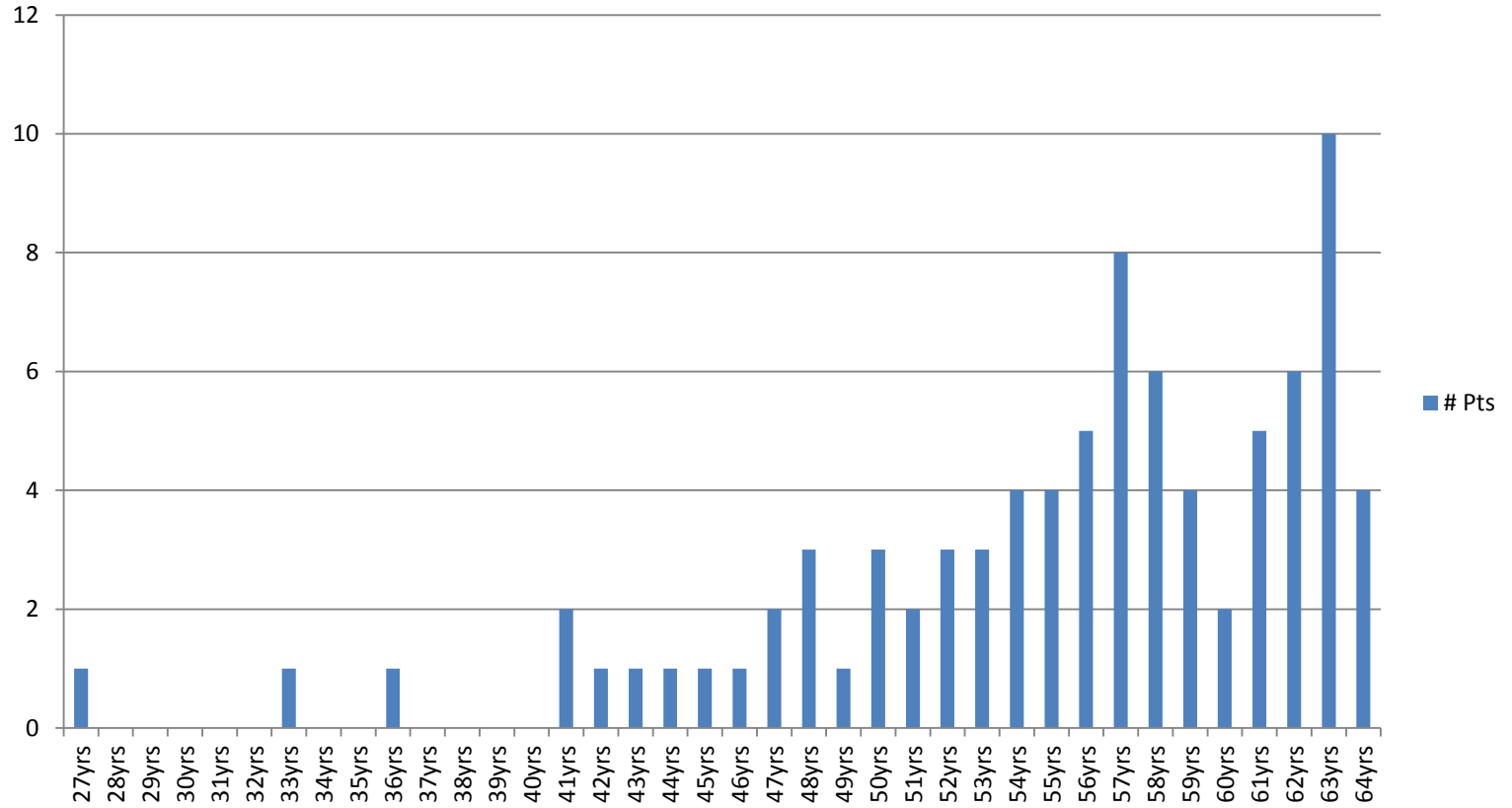
- N (85)
- Mean Age (55.19)
- F/M (50/35)
- MMSE Initial (27.25) SD((3.34))
- MMSE F/U (25.45) SD((4.51))
- MMSE (NH) (25.67) SD((1.16))

Variable	N	Descriptive
Age (mean (SD))	85	55.19 (7.51)
Age Groupings:		
25-29.99	1	1.2%
30-34.99	1	1.2%
35-39.99	1	1.2%
40-44.99	5	5.9%
45-49.99	8	9.4%
50-54.99	15	17.6%
55-59.99	27	31.8%
60-64.99	27	31.8%
Gender:		
Male	35	41.2%
Female	50	58.8%
SW Consult:		
No	48	56.5%
Yes	37	43.5%
Home at diagnosis:		
No	3	3.5%
Yes	82	96.5%
Last recorded location:		
Home	77	90.6%
Hospice	1	1.2%
Nursing Home	6	7.1%
Do not know	1	1.2%

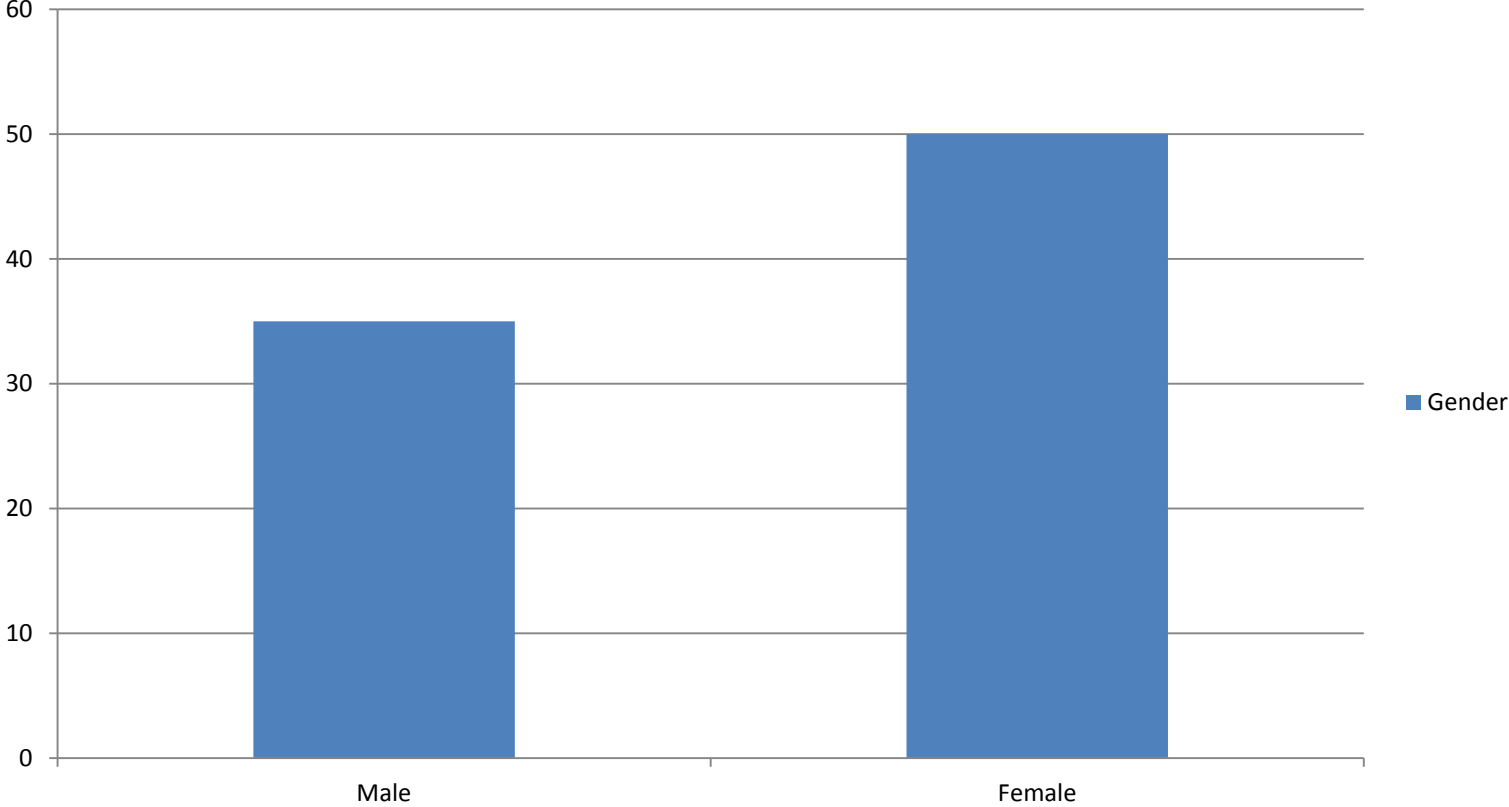
Variable	N	Descriptive
Diagnosis: Overall		
ETOH	2	2.4%
HIV	1	1.2%
MS	10	11.8%
Neoplasm	1	1.2%
Neurodegenerative	50	58.8%
AD	19	
FTD	13	
MCI	9	
MIX	3	
PCA	1	
PD	5	
Other	2	2.4%
CNOS/Behcet	1	
NPH	1	
TBI	10	11.8%
ADD+MDD	9	10.6%
ADD	6	
MDD	3	
First MMSE (mean (SD))	60	27.25 (3.34)
MMSE follow-up (1-2yrs) (mean (SD))	20	25.45 (4.51)
MMSE follow-up (nursing home) (mean (SD))	3	25.67 (1.16)

Variable	N	Descriptive
Work-up:		
1	20	23.5%
MRI	13	
NP	7	
2	25	29.4%
MRI + NP	13	
MRI + PET	7	
MRI + SPECT	3	
PET + NP	2	
3	32	37.6%
MRI + PET + NP	22	
MRI + PET + SPECT	1	
MRI + SPECT + NP	9	
4	1	1.2%
None	7	8.2%
MRI:		
No	16	18.8%
Yes	69	81.2%
PET:		
No	52	61.2%
Yes	33	38.8%
SPECT:		
No	71	83.5%
Yes	14	16.5%
Neuropsych:		
No	31	36.5%
Yes	54	63.5%

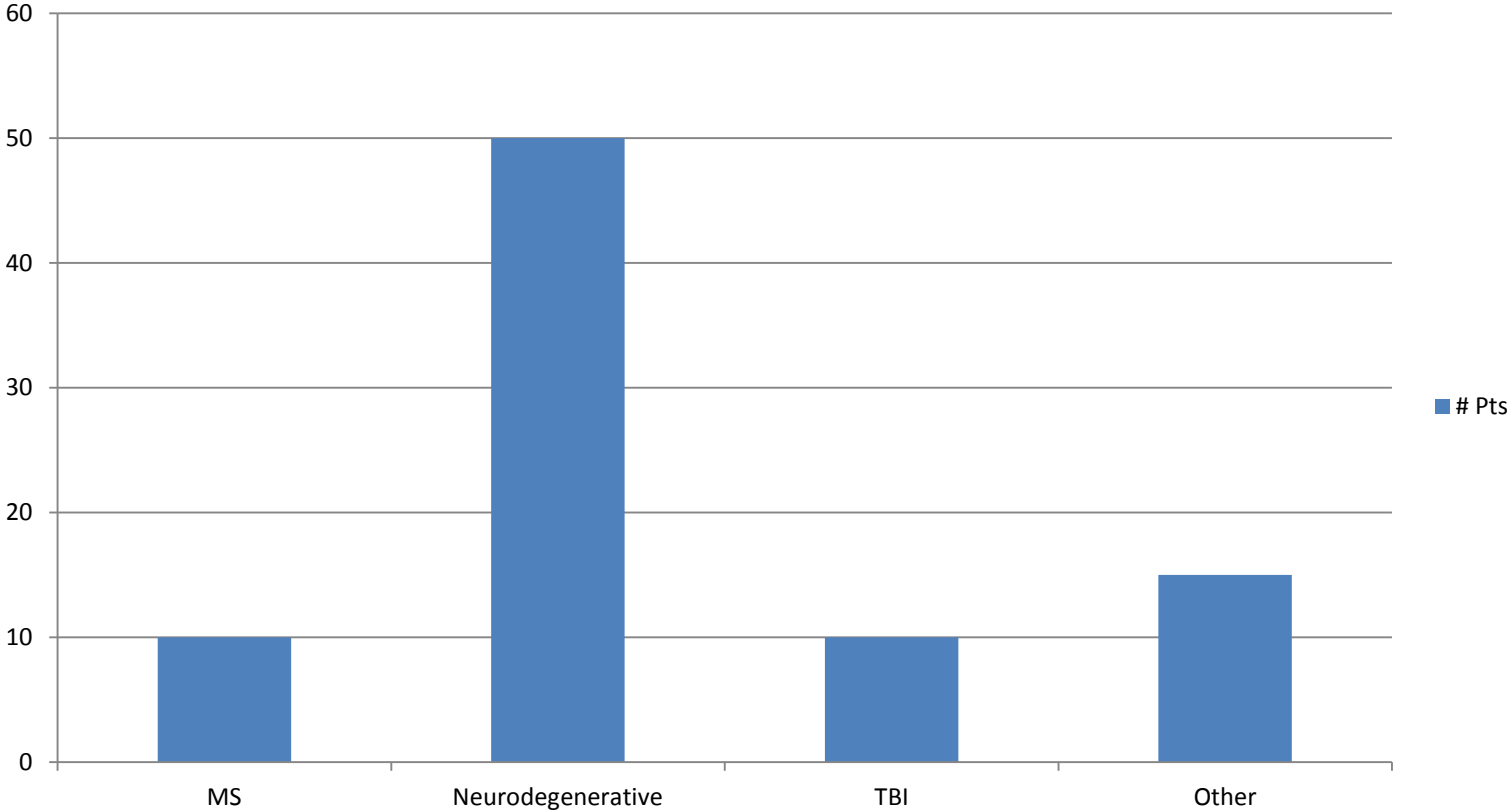
Age



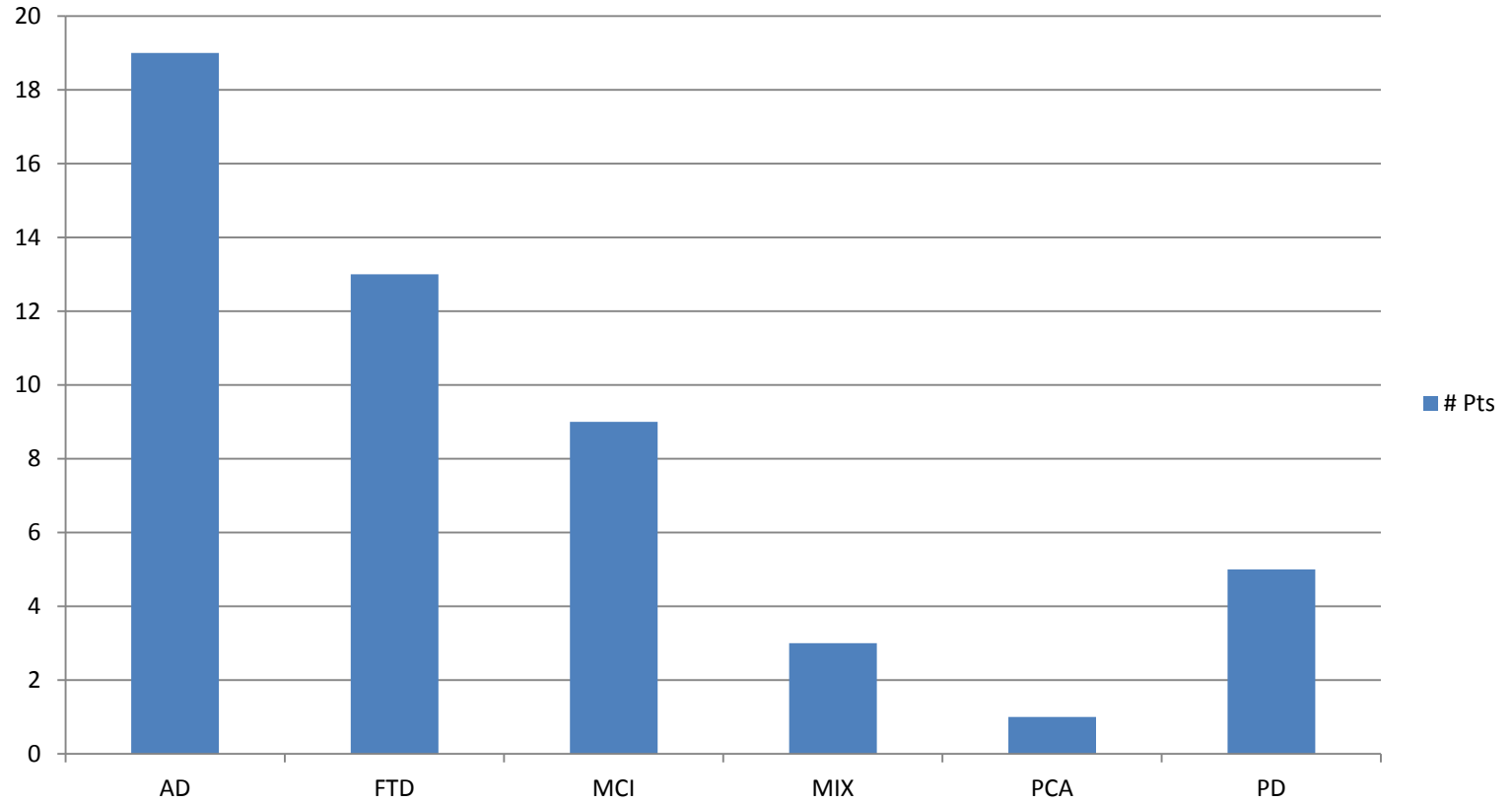
Gender



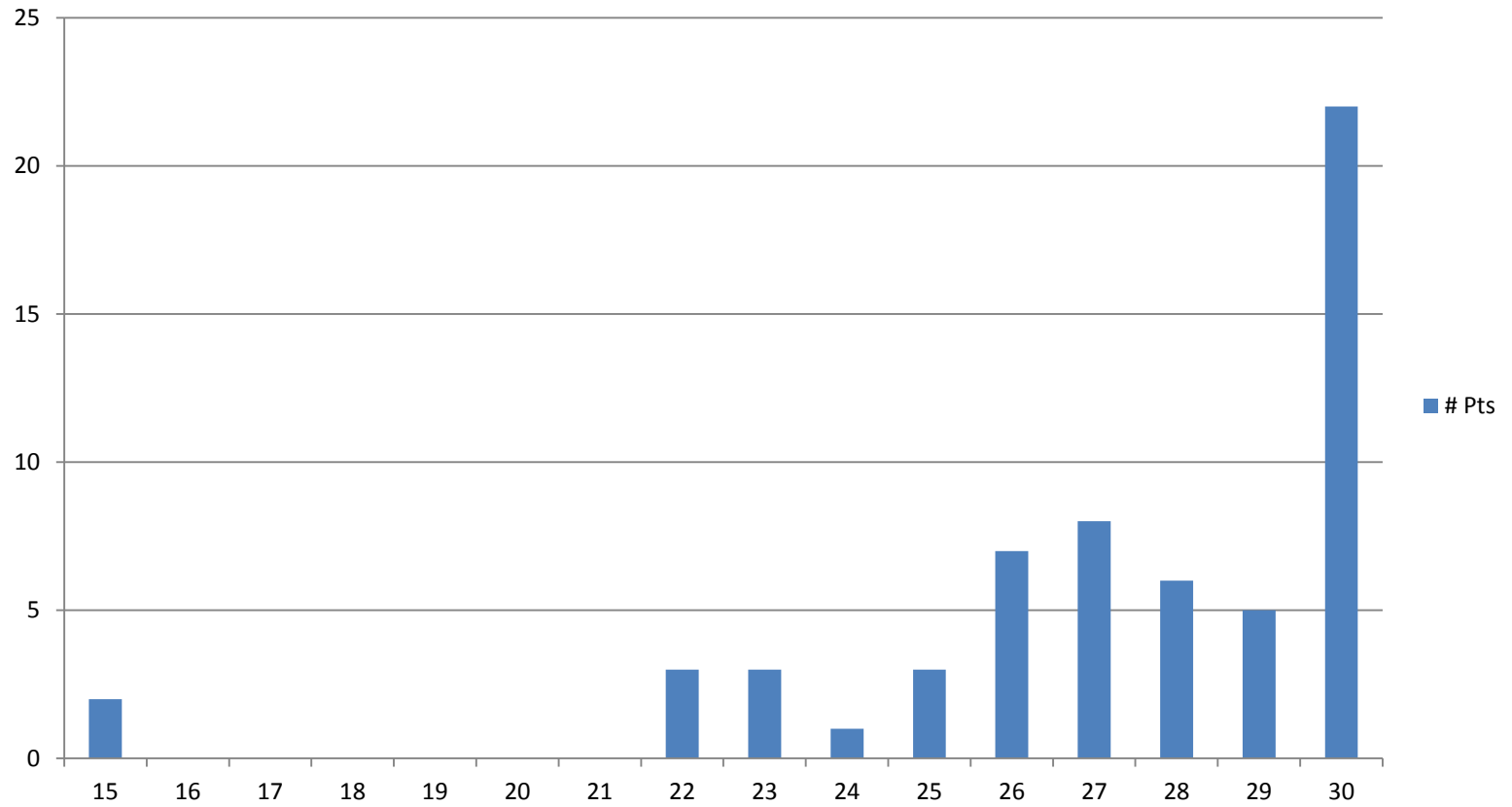
Diagnosis



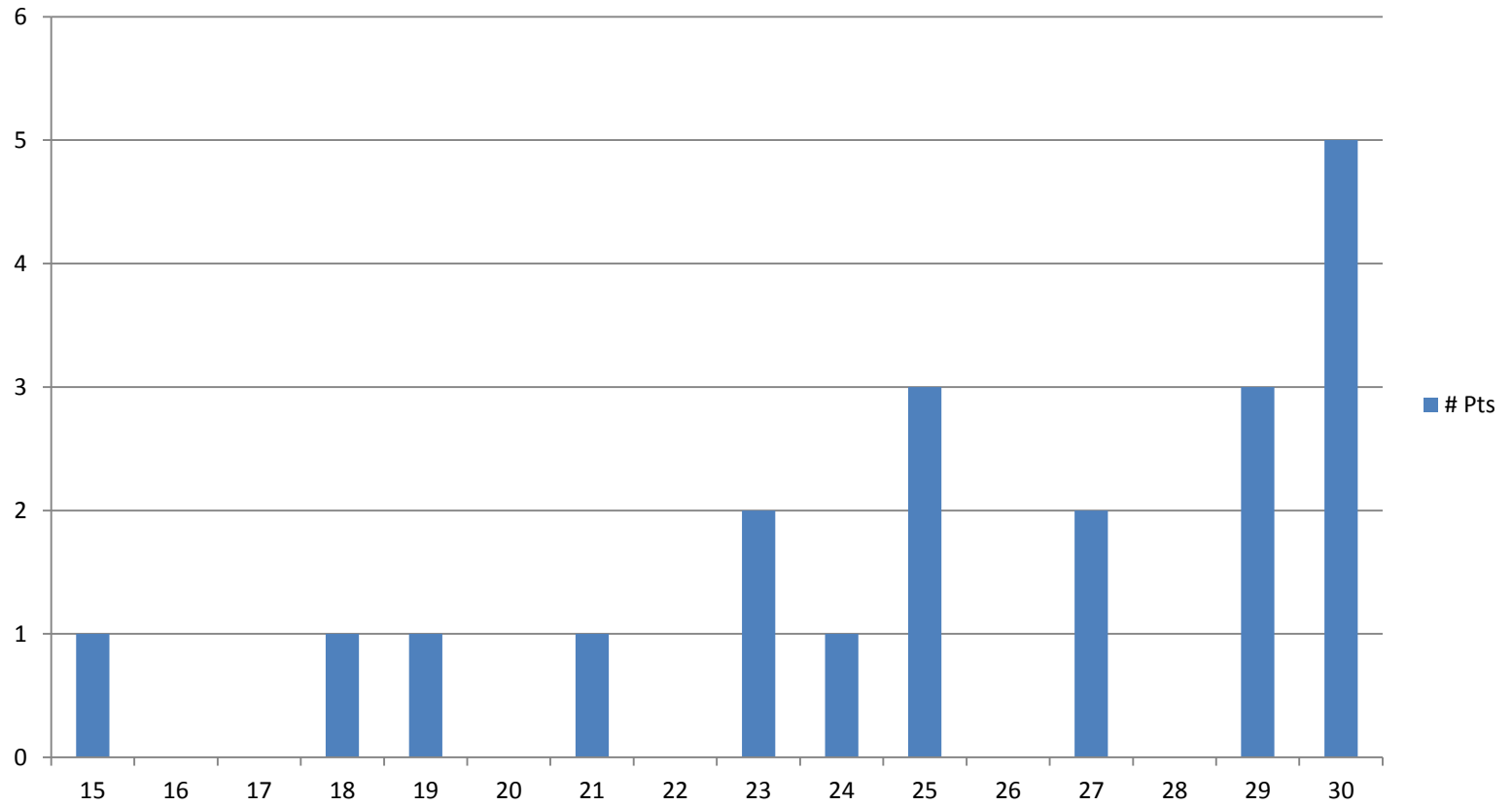
Neurodegenerative Diagnosis



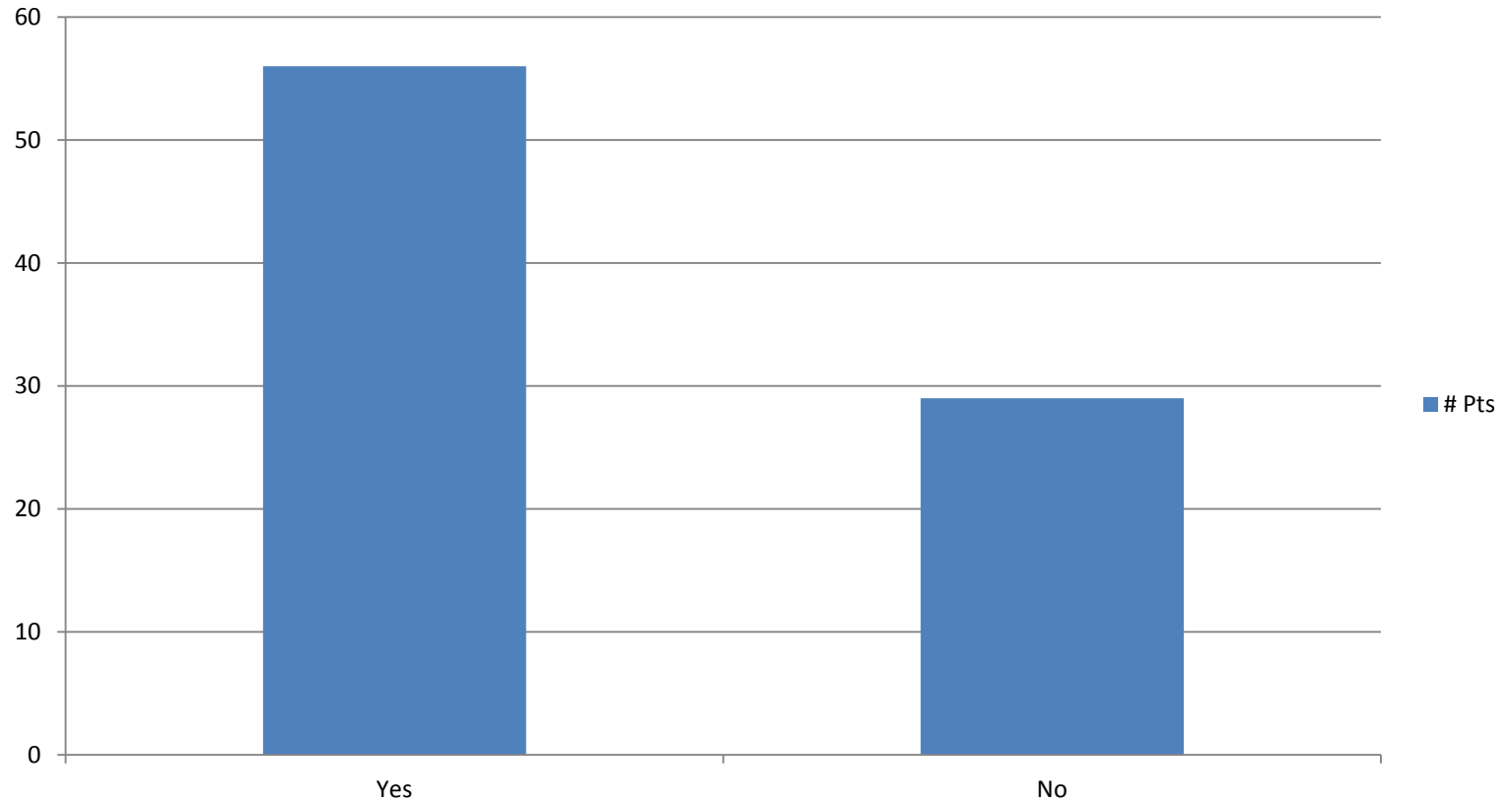
Initial MMSE



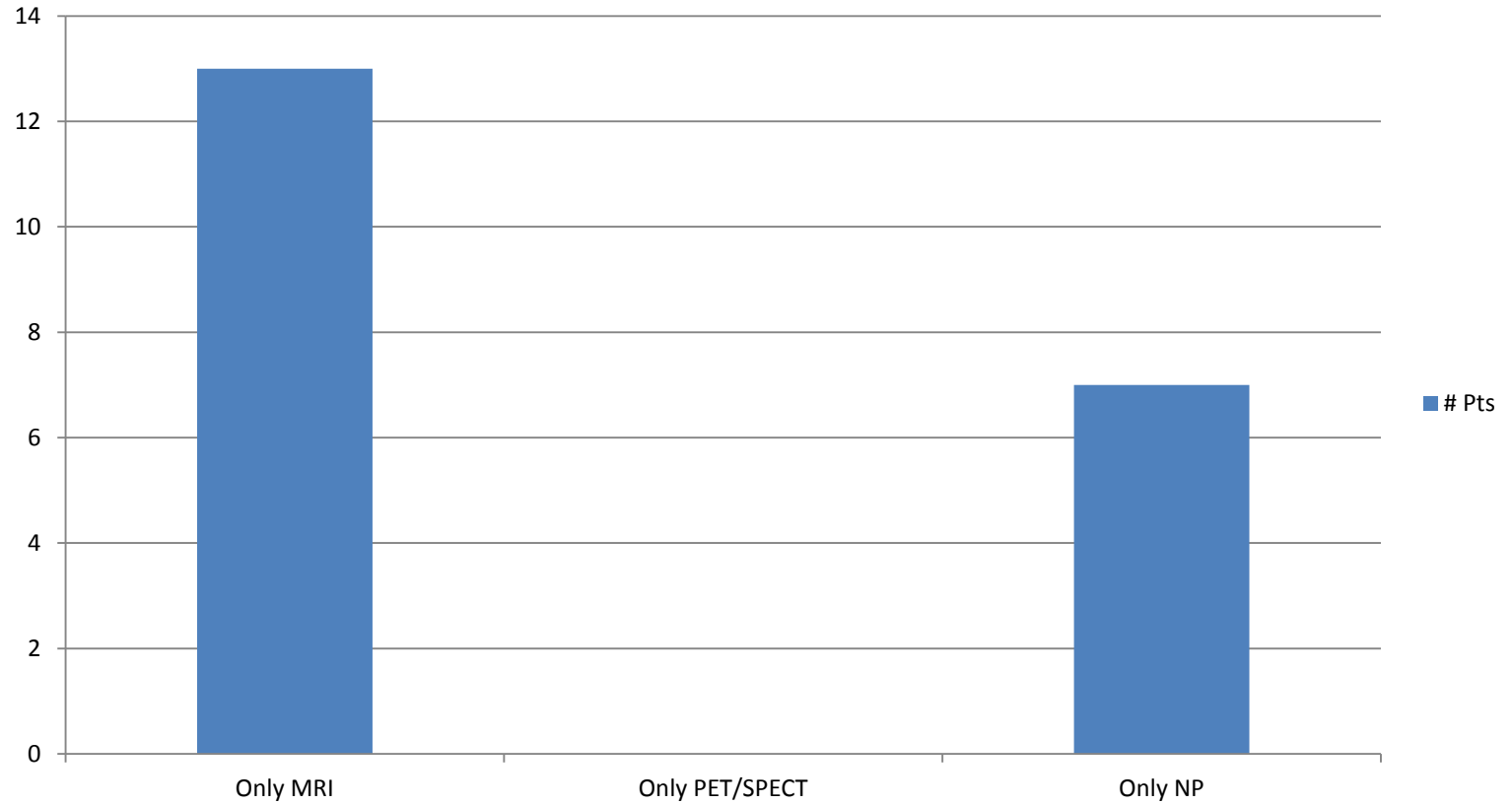
Follow-up MMSE



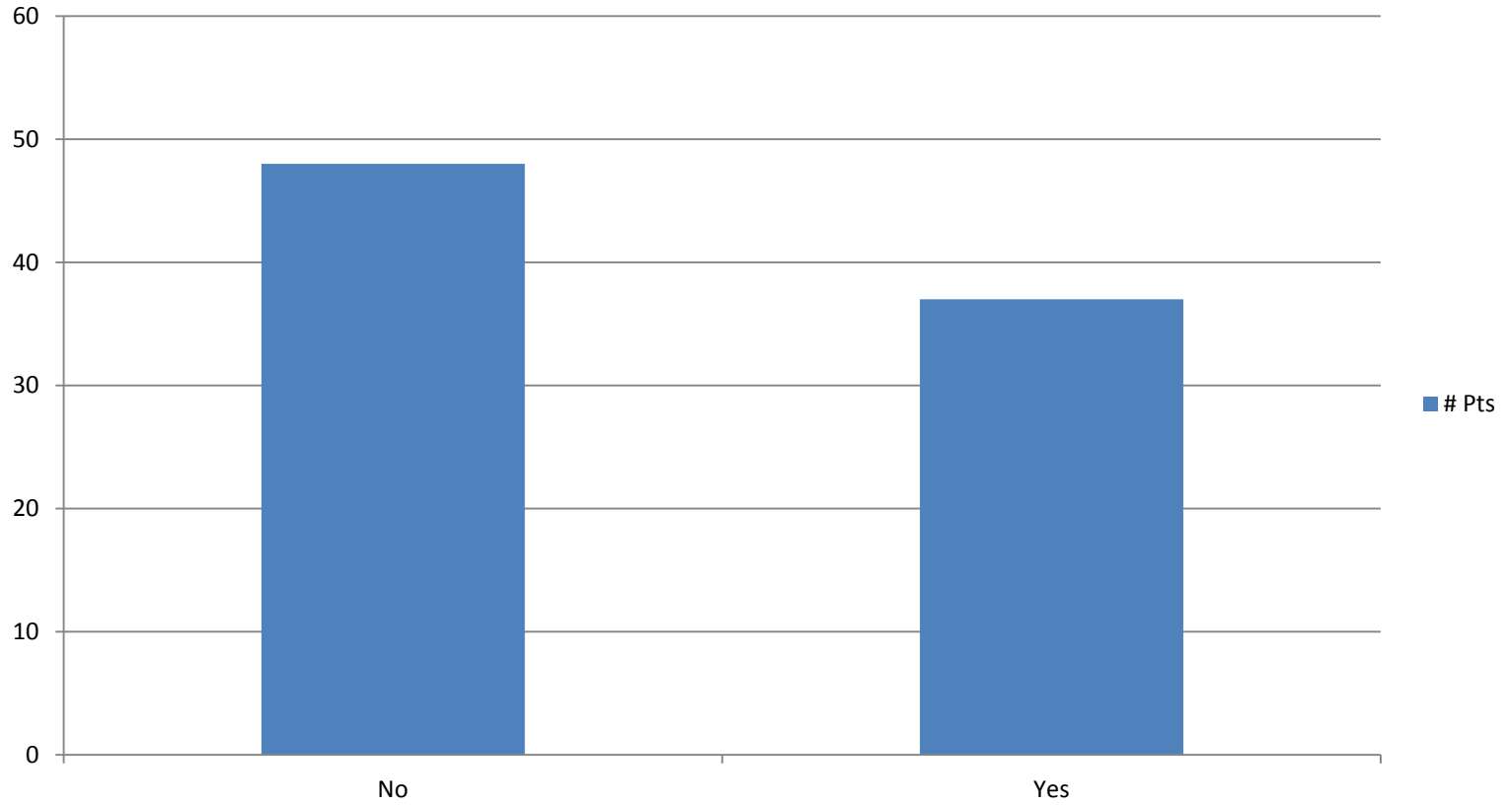
Work-Up (yes/no)



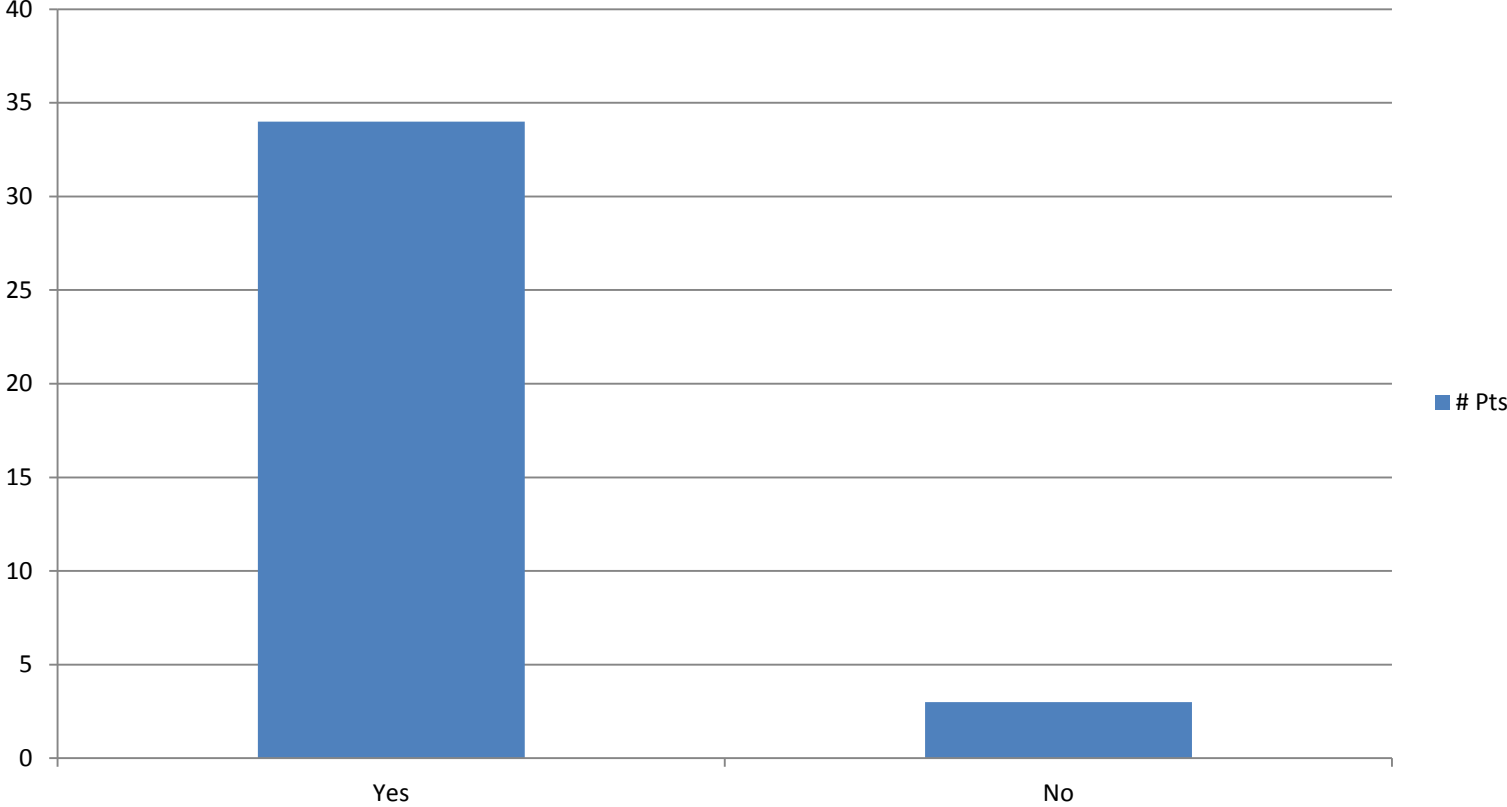
Work-Up (types)



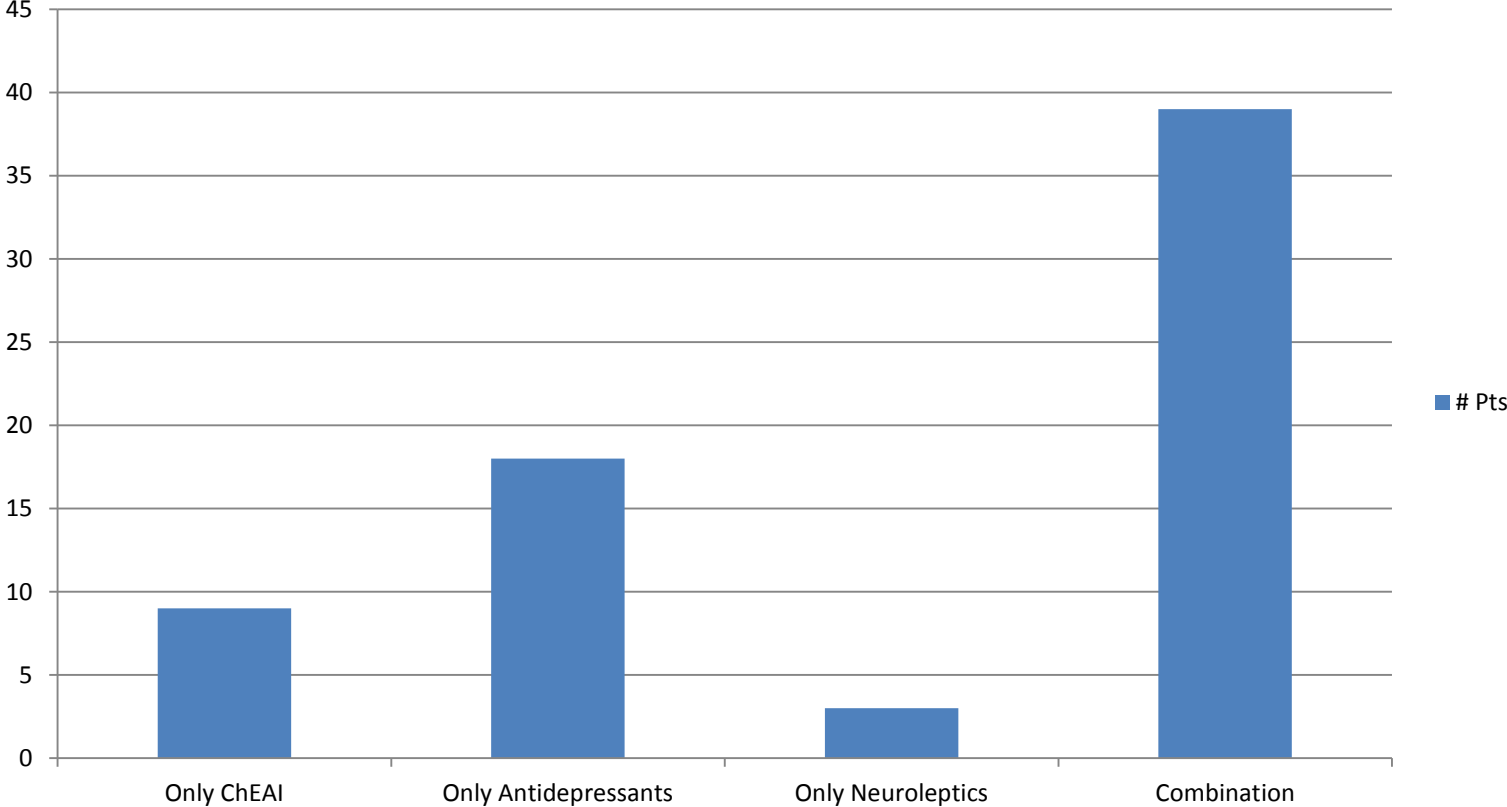
Social Work Consult



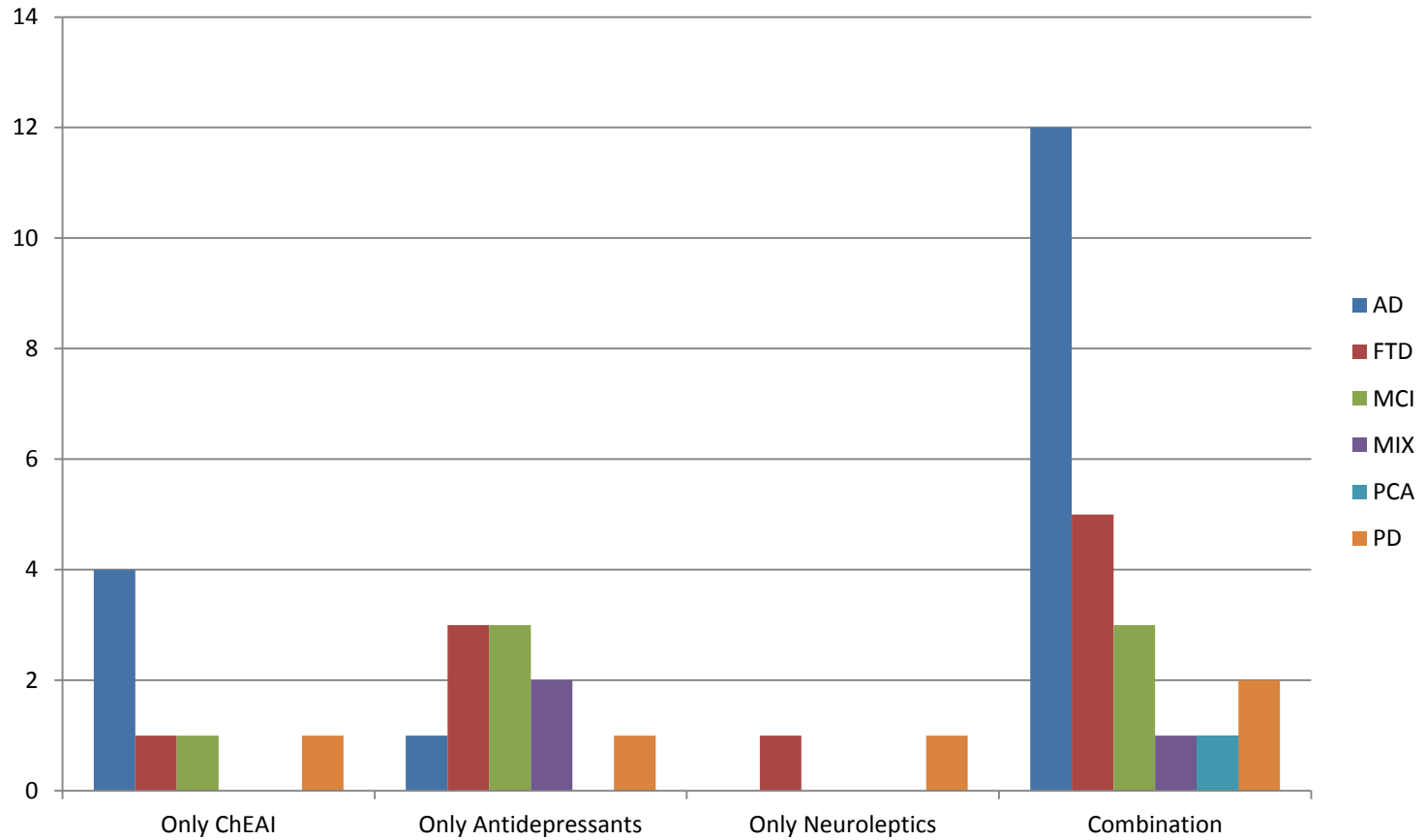
Social Work Intervention



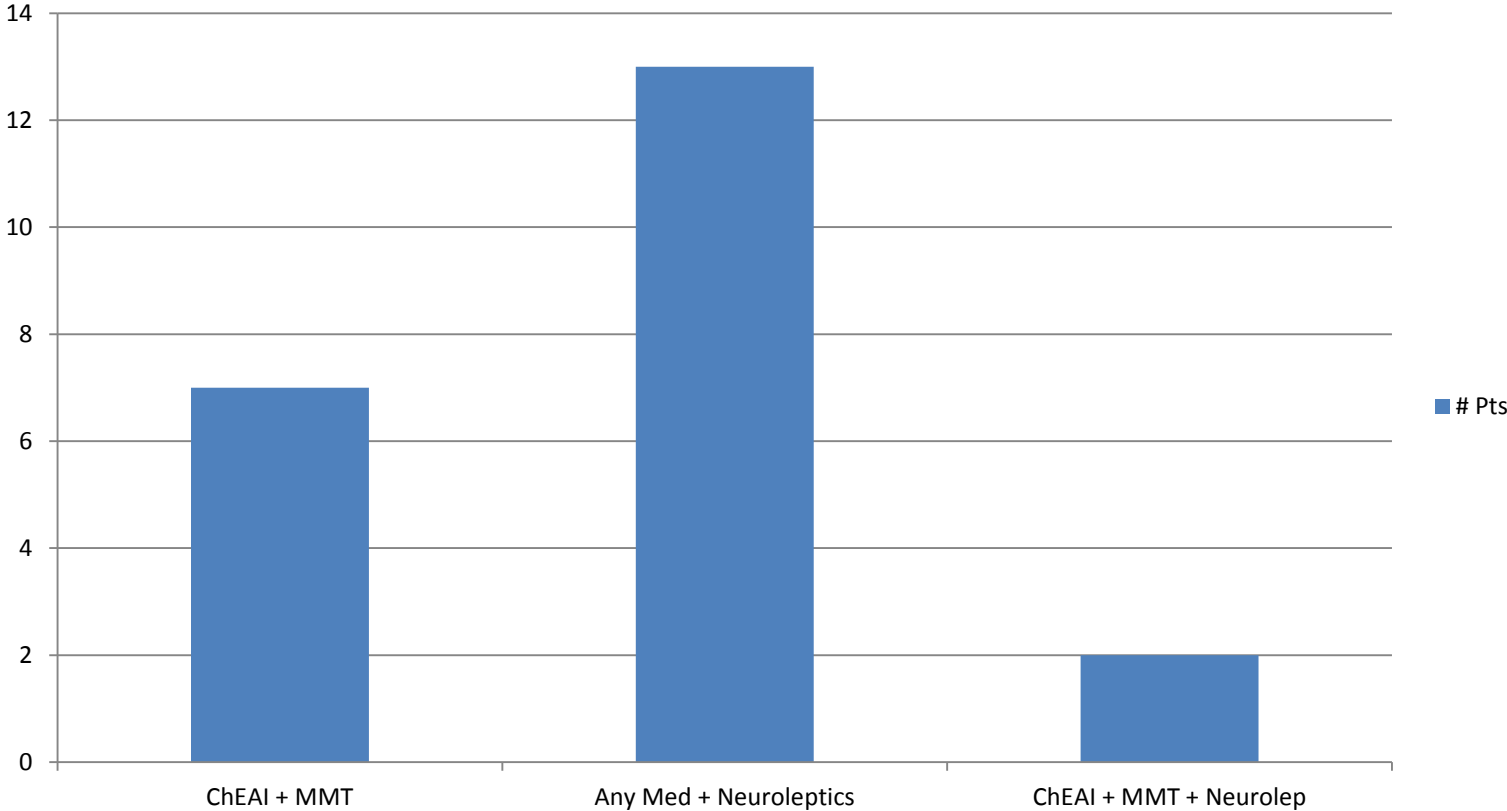
Medication, Table #1



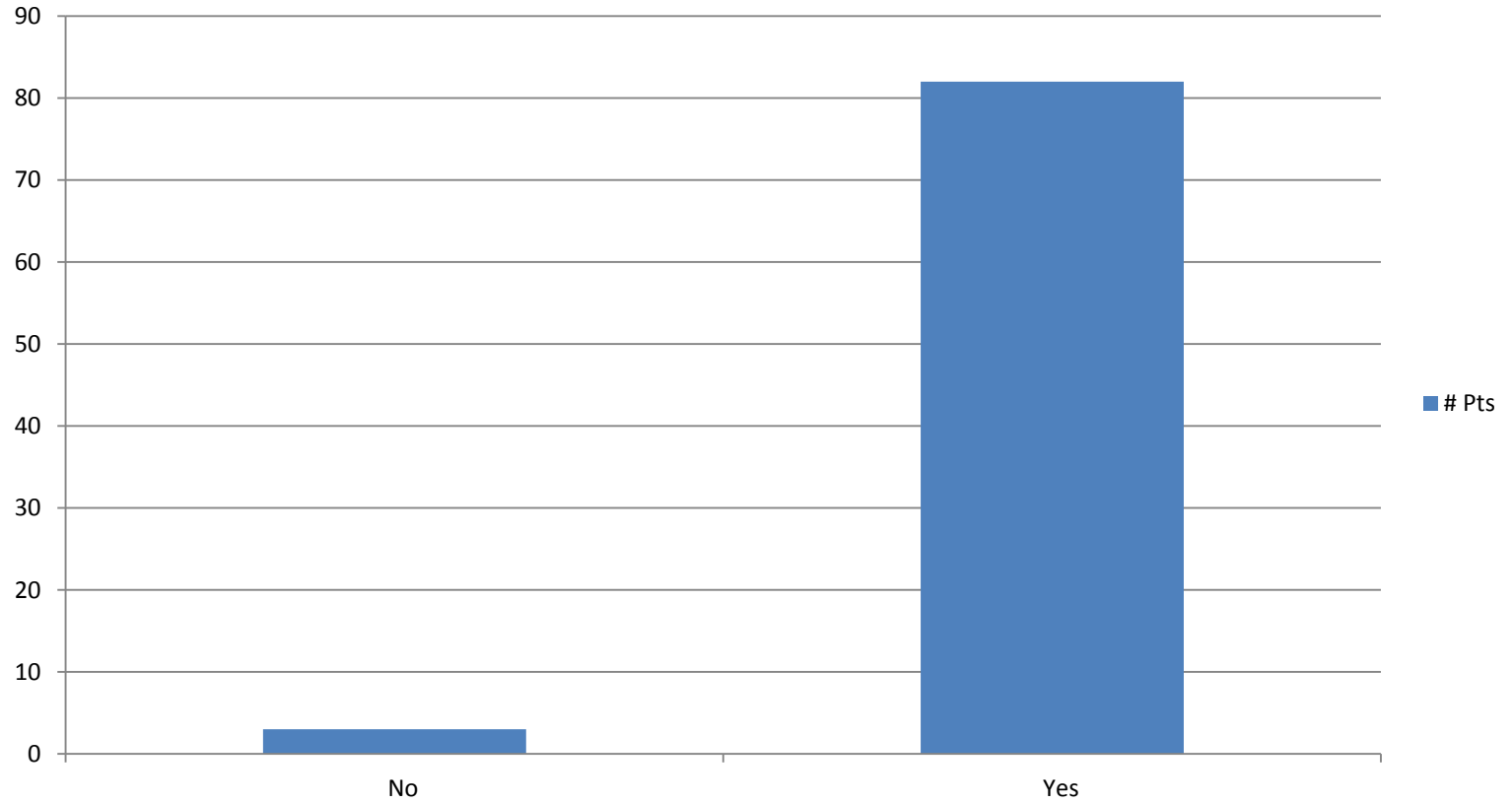
Medication by Neurodegenerative Diagnosis



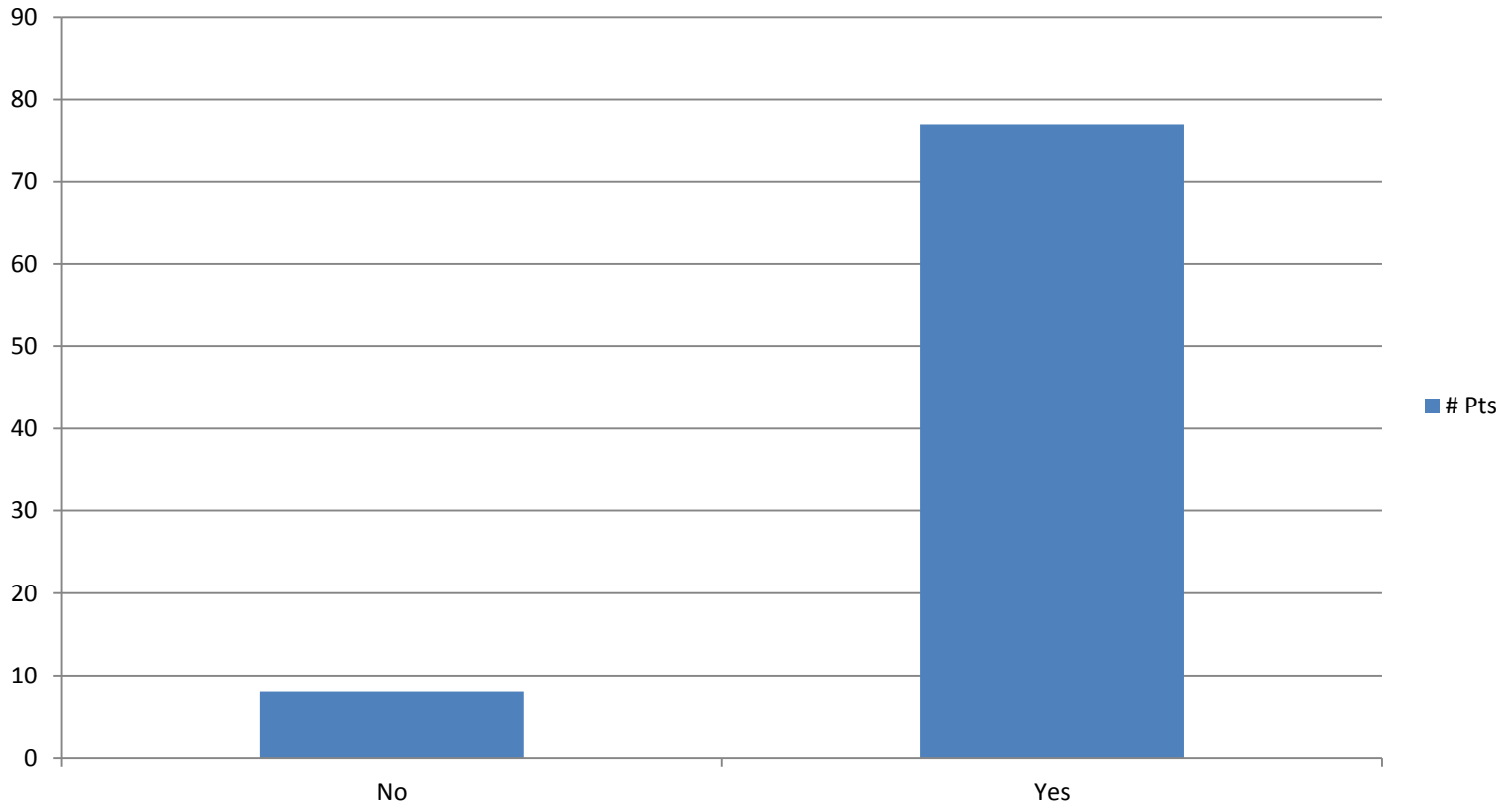
Medication, Table #2



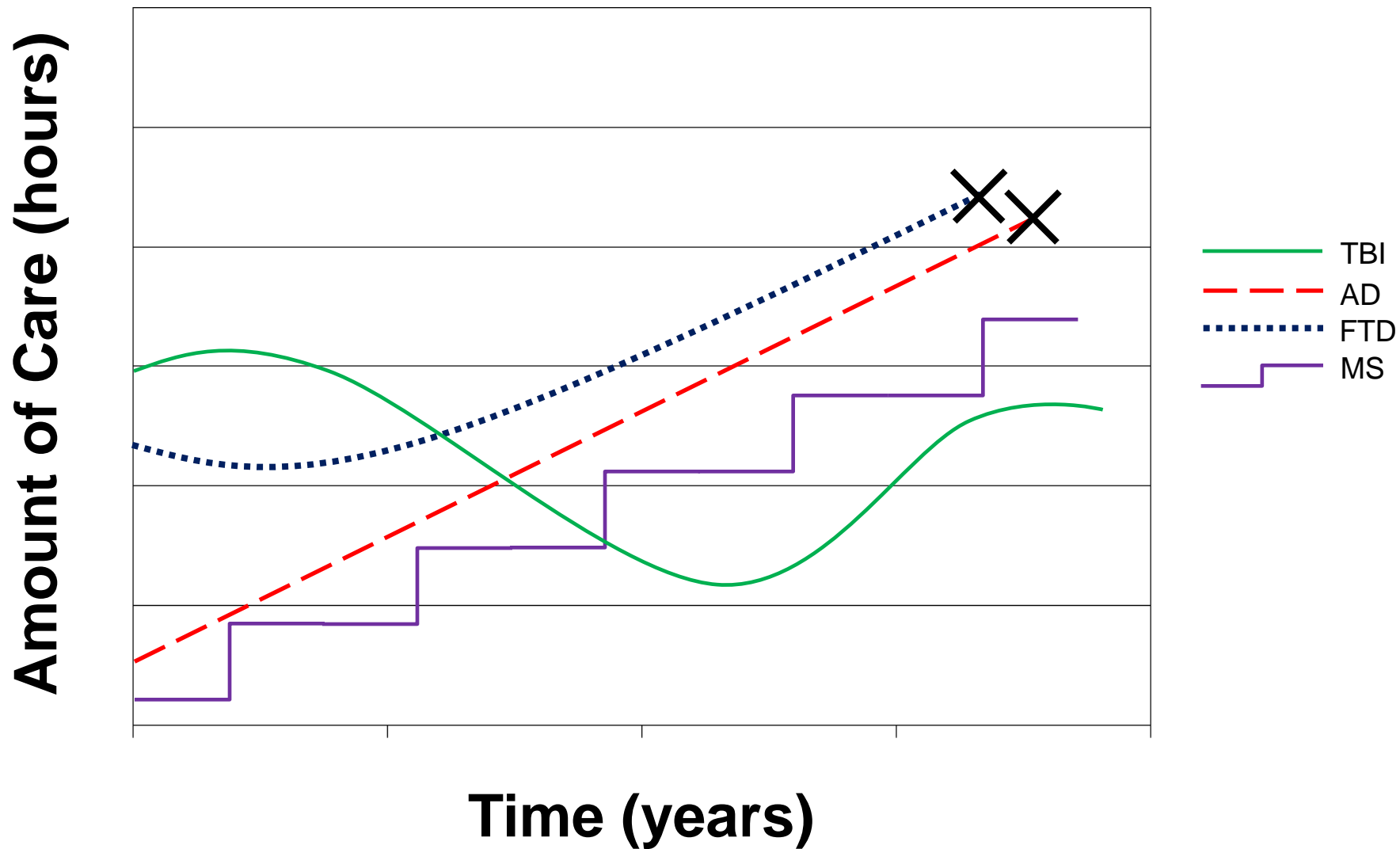
Home at Diagnosis



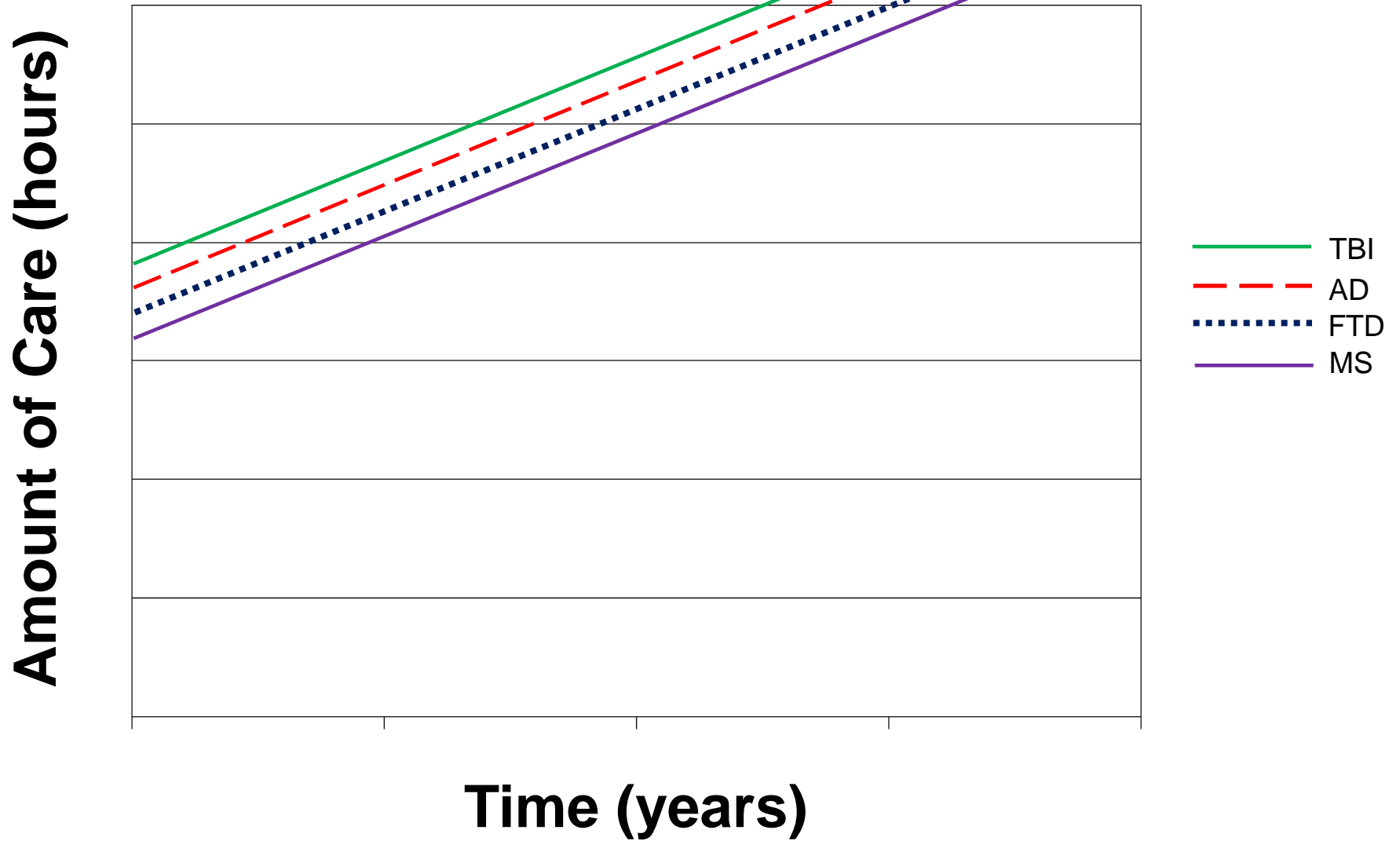
Home Now



Amount of Medical Care over Time



Caregiver Burden over Time





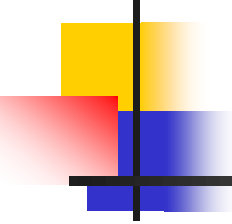
Current State of Affairs in Massachusetts

- 428 Nursing Homes
- 128 Dementia Units
- 213 Assisted Living Residences
- 102 offer some sort of special care
- If able to pay \$\$ -----most will accommodate
- [Benchmark Group]



Current State of Affairs in Massachusetts

- New legislature being proposed
- Help family access Mass Health quickly
[even if spouse has some money]
- Can use PCA and move to NH [covered by
Mass Health]
- EOD is an inclusion criteria



Mass Health and Common Health Care: Who is eligible?

*Cut-off Mass Health :

1201\$/mo for Individual

1616 \$/mo for Couple

*Cut-off Common Health Care:

1355\$/mo for Individual

1823\$/mo for Couple

Assistance Programs
Updated Data
Sept 2010

Can serve any elder + disabled

Long Term Care
Options Counseling

State Executive Office
of Elders Affairs
[State Funding]

MRC Home Care
Assistance

Family Caregiver
Program
[Federal Funding]

Develop Future Plans

27 Aging Service
Access Points (ASAP)
[Regional Agencies]

Can serve
people 18-59
yrs. w/
disability,
living alone

Can serve people:
- > 60 yrs.
- Any **AD**
- Grandparent caring
for grandchildren

ASAP

If Mass. Health, PCA

Local ASAP

Not accepting
referrals and
\$\$\$

Not accepting
referrals

Meals

Personal Care

Funding for Adult
Health

Can serve age < 60 yrs. if **AD, FTD, DLB**, but:
- Sliding scale
- Income guidelines change overtime
- "Place out" → Private homecare
Does not serve: **TBI, MS, others**





Concerned?... We are!!

Major areas of concerns

1. Extensive \$\$ work-up, combo meds, SW consults and yet NO tangible change in what we are able to do so far...
2. Access to services
3. Care giving- YOU
4. Family burden and responsibility
5. Driving?
6. ADL's and IADL's : The list is long...





Thank you!

