



Clinical Audit Research Evaluation

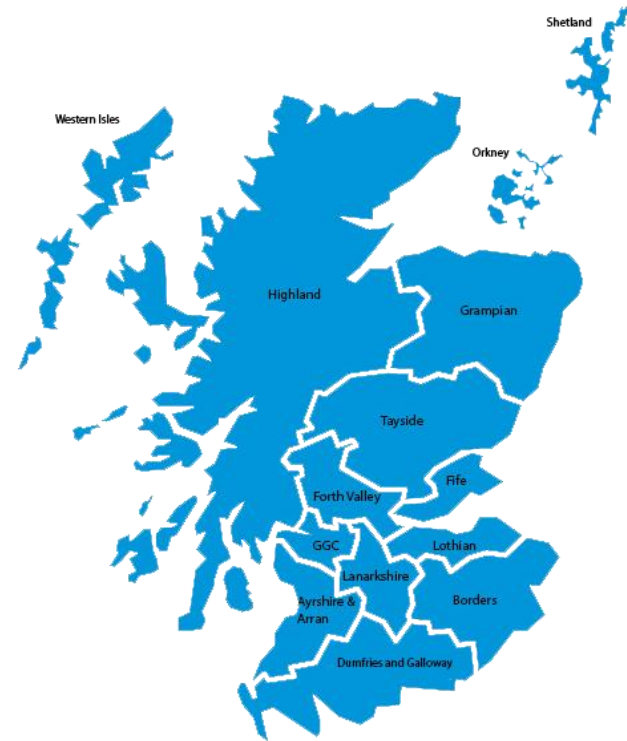
Improving Standards, Building Hope, Adaptive nursing

Judy Newton , MND nurse consultant
Cradle to Grave 2018



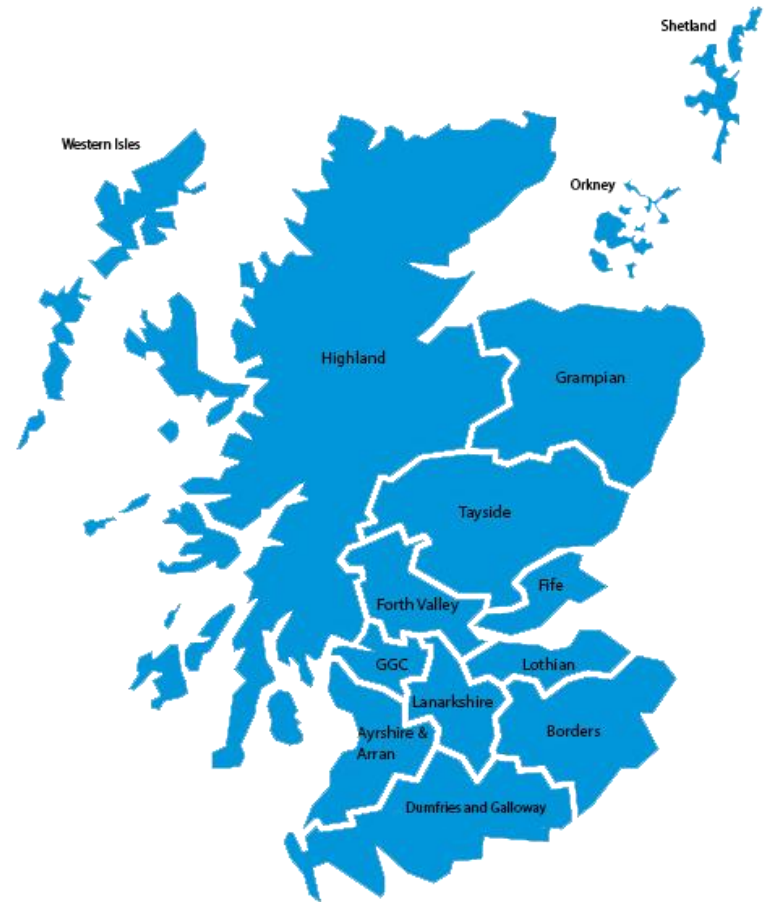
Scope of the problem

- **Your experiences of degenerative diseases:**
 - How many of you have cared for patients with progressive neurological conditions
 - Were there particular challenges with diagnosis, and subsequent management?



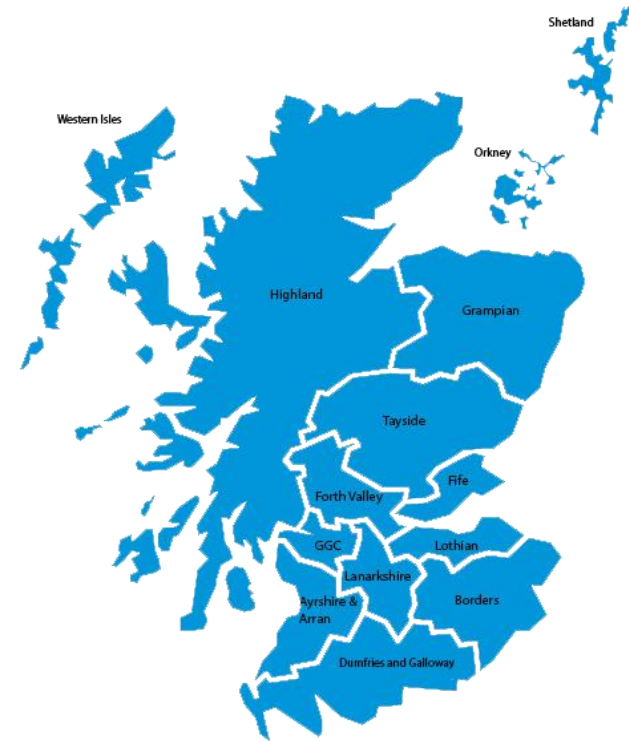
Rare diseases

- Progressive supranuclear palsy
- Lewy Bodie Dementia
- Parkinson's Disease
- Inclusion Body Myositis
- BVVL; Kennedy's
- MND
- Early onset dementias



Scope of the problem

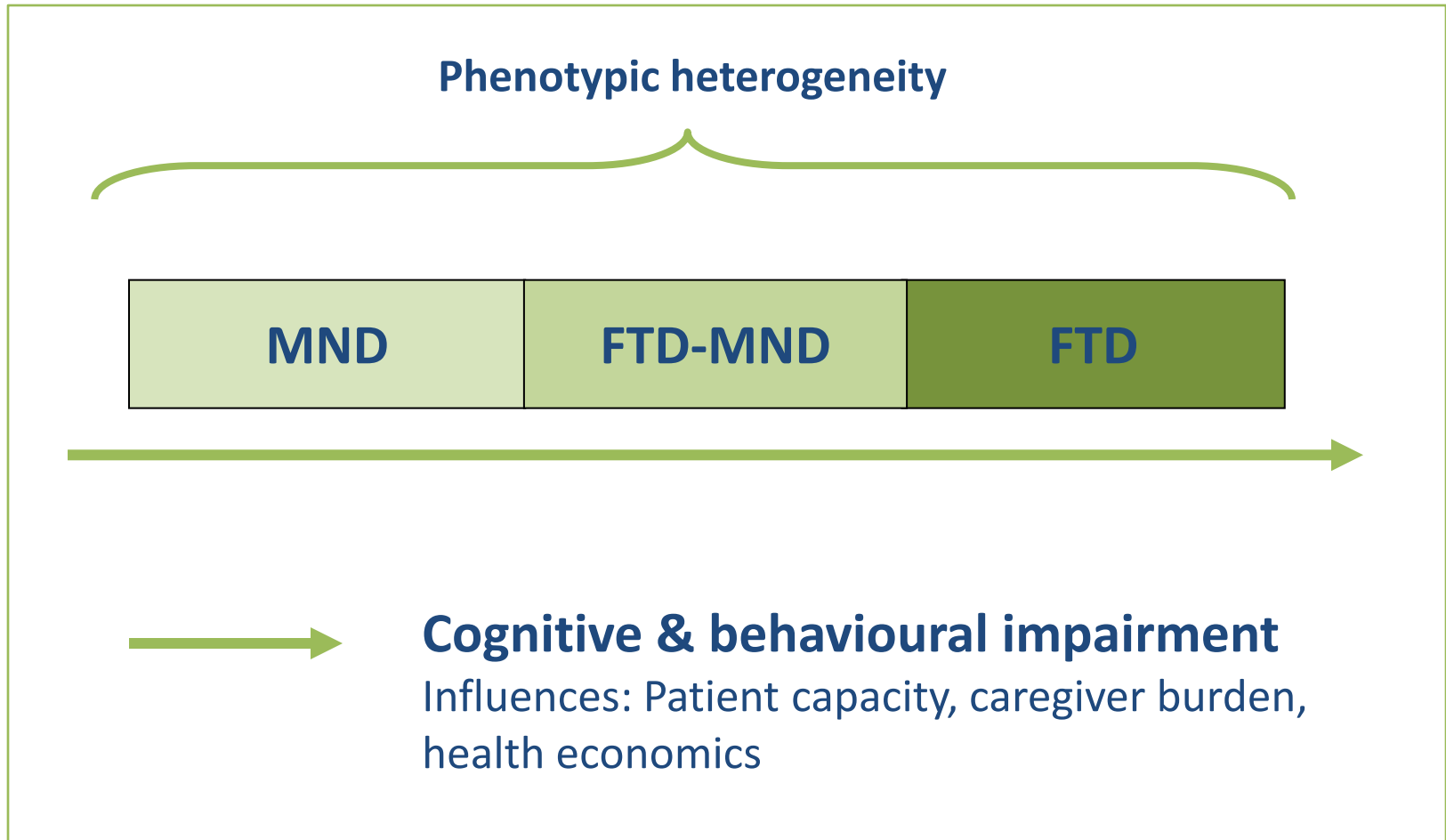
- A progressive & fatal disease
- Neurodegeneration affects varying parts of the brain and spinal cord
- Usually leads to progressive weakness of:
 - Bulbar
 - Cognitive decline
 - Limb
 - Thoracic
 - Abdominal muscles



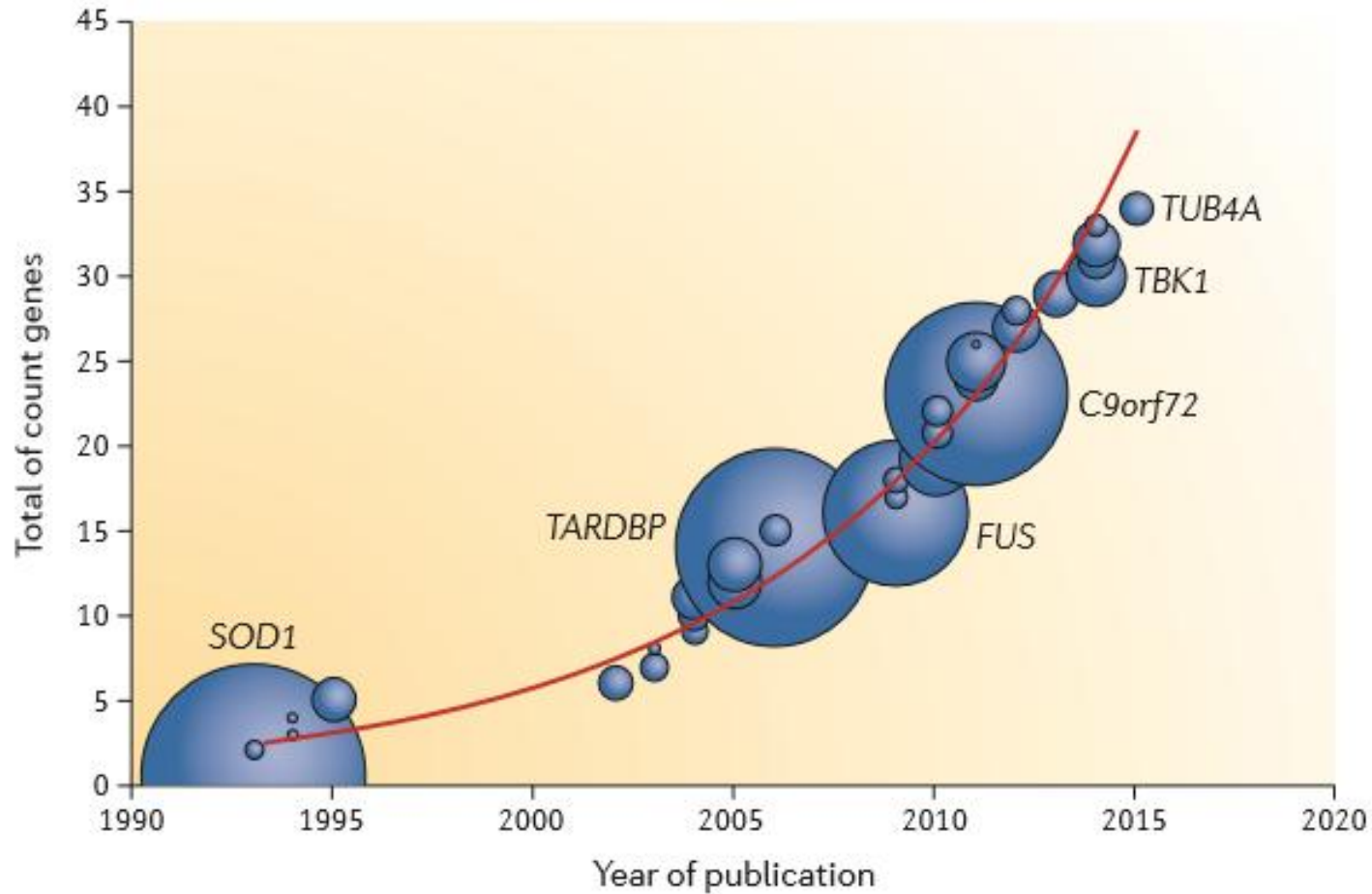
Symptoms

- Muscle wasting and weakness
- Fasciculations
- Cramps
- Speech and swallowing problems
- Respiratory difficulties
- Neuropsychiatric

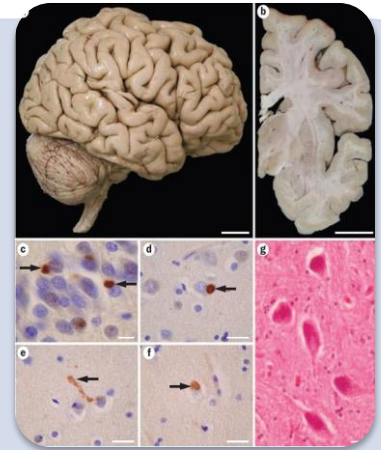
Phenotypic spectrum of diseases PD , MND , MS ,



Advances in genetics of MND



Al-Chalabi et al Nature Reviews Neurology (2016)



Genetics

C9ORF72

SOD1

OPTN

TARDBP

FUS

VCP

TBK1

Clinical syndrome

Motor and cognitive/
behaviour

Neuroimaging

Differential atrophy

Pathology

Tau
TDP-43

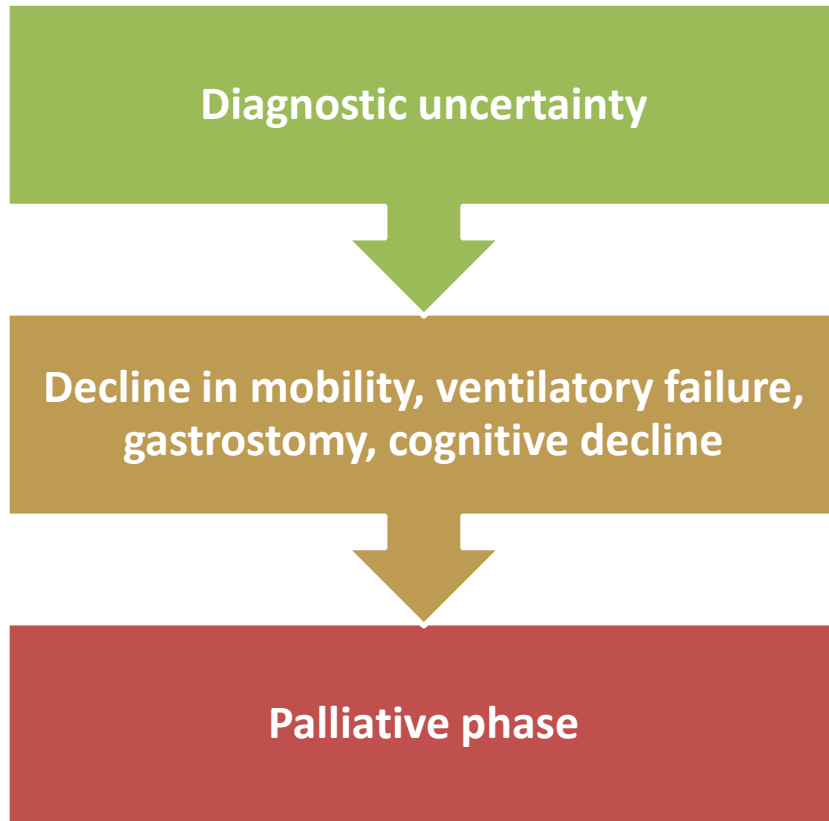
FUS

UPS

Diagnosis of diseases

- Diagnosis based on
 - Symptoms
 - Clinical examination findings
 - Neurophysiology
 - Neuroimaging
 - Blood tests – myopathy/neuropathy
 - Lumbar puncture
 - Post mortem in some cases

The patient journey



- Up to 1 year

- 2-3 years

Why me?

What
symptoms will
I develop?

Will my
memory be
affected?

Will I pass this
on to my
children?

How long do I
have?

Is there a
cure?



Patients & carers define of our priorities

Different diseases same nursing care

- Parkinson's Disease
- Fronto-temporal dementia (FTD) young and old
- Alzheimer's Disease
- MND
- MS
- Rare conditions
- Kennedy's disease
- Spinal Muscle Atrophy
- Inclusion body myotitis
- Brown –Violetto Van Lerre Syndrome BVVLS
- Post polio syndrome
- Progressive supra nuclear palsy

posture

breathing

secretion
management

pain

emotional
care

supportive
treatment

disease
charities

neuro teams
happy to
advise



Take home message

- If you can't pronounce it don't panic - most neuro nurses can't either !
- Usually one of the specialist nurses can sign post to help from more generic speciality
- Nurse your patient as you would for any of the symptoms

Questions and thanks

