ALL WALES MND STUDY DAY

WHY ACCESS TO CLINICAL PSYCHOLOGY IS IMPORTANT FOR PEOPLE LIVING WITH MND

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THE PLAN

- What are the psychological needs of people living with and affected by MND?
- Embedding psychological care within services.
- The Future!

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WHAT ARE THE PSYCHOLOGICAL NEEDS OF PEOPLE LIVING WITH AND AFFECTED BY MND?

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MND

THE PSYCHOLOGICAL CHALLENGES

“ A life
of unremitting loss
and uncertainty”

- **Diagnosis**

Clinical levels of depression most often occur within a year of diagnosis (Mora et al, 2013)

Shock, uncertainty, "why me?", acceptance/adjustment, understanding MND, understanding treatment options

- **Coping with Change**

Distress tends to be higher at times of change (Flemming et al, 2020)

Loss of role, changed identity, changes in relationships, changes in physical ability, loss of speech, loss of autonomy, threatened future

- **End of Life**

Facing death, making decisions about treatment and care.

COGNITION

Approximately 50% of PLW MND experience some level of change early in the disease (Goldstein & Abrahams, 2013), with the percentage increasing to 80% by the late stages of the disease (Crockford et al, 2017)

For a smaller but substantial group (roughly 15% of PLW MND), these changes are significant enough that they would also meet the criteria for a diagnosis of frontotemporal dementia (Ringholtz et al, 2005)

These cognitive and behavioural changes can have devastating consequences for the person living with MND and those around them.

Clinically, the changes can lead to challenges in many areas of life, including decision making, everyday care, increased risks of harm, and changes in relationships.

Behavioural changes also predict higher levels of burden for MND carers.

National Institute for Health and Clinical Excellence (NICE, 2016) recommend that patients with MND have access to tailored neuropsychological assessment.

WHO ELSE IS AFFECTED BY MND?

MND carers also experience high levels of distress and report feeling similar losses to those living with the disease due to watching their family member lose capability and independence.

Recent research suggests that family members and friends caring for someone living with MND experience clinical levels of distress at least as often, if not more often, than those they care for; anxiety levels are particularly high .

"I come to a point where I mentally got too exhausted. I used to come home and just cry and cry. I was so lucky to be given some counselling sessions with Sian. It was just like this angel had come into my life."

Evangeline DiMichele
Carer of mum, Marie who died of MND

THE PSYCHOLOGICAL NEEDS OF THOSE WITH MND IN SOUTH WALES

- Transforming care audit- suggested this as significant area of unmet need not previously provided.
- In 2019, a service evaluation was conducted to capture the psychological needs of patients living with MND and their families in South Wales.
- The results indicated that 44% of the patients in included in the study would be referred to a psychology service if one was available unmet.
- The results suggested that the level of psychological need varied according to length of time since diagnosis, with the highest level of need occurring between 24-36 months post diagnosis (100% need), and between 0-6 months post diagnosis (57% need).
- The lowest level of psychological need was for patients who had been diagnosed 48 months ago or longer (25%).
- The needs detailed for referral to psychological services include: adjustment to diagnosis, anxiety, low mood, sleep disturbance, and current counsellor lacking MND specific knowledge.

RICHARD'S STORY

WHAT SHOULD ACCESS TO CLINICAL PSYCHOLOGY LOOK LIKE?

"Psychological care should be integrated with physical care in an **organised, systemic and practical** way. Mental health significantly impacts patient's quality of life, more so than physical comorbidities"

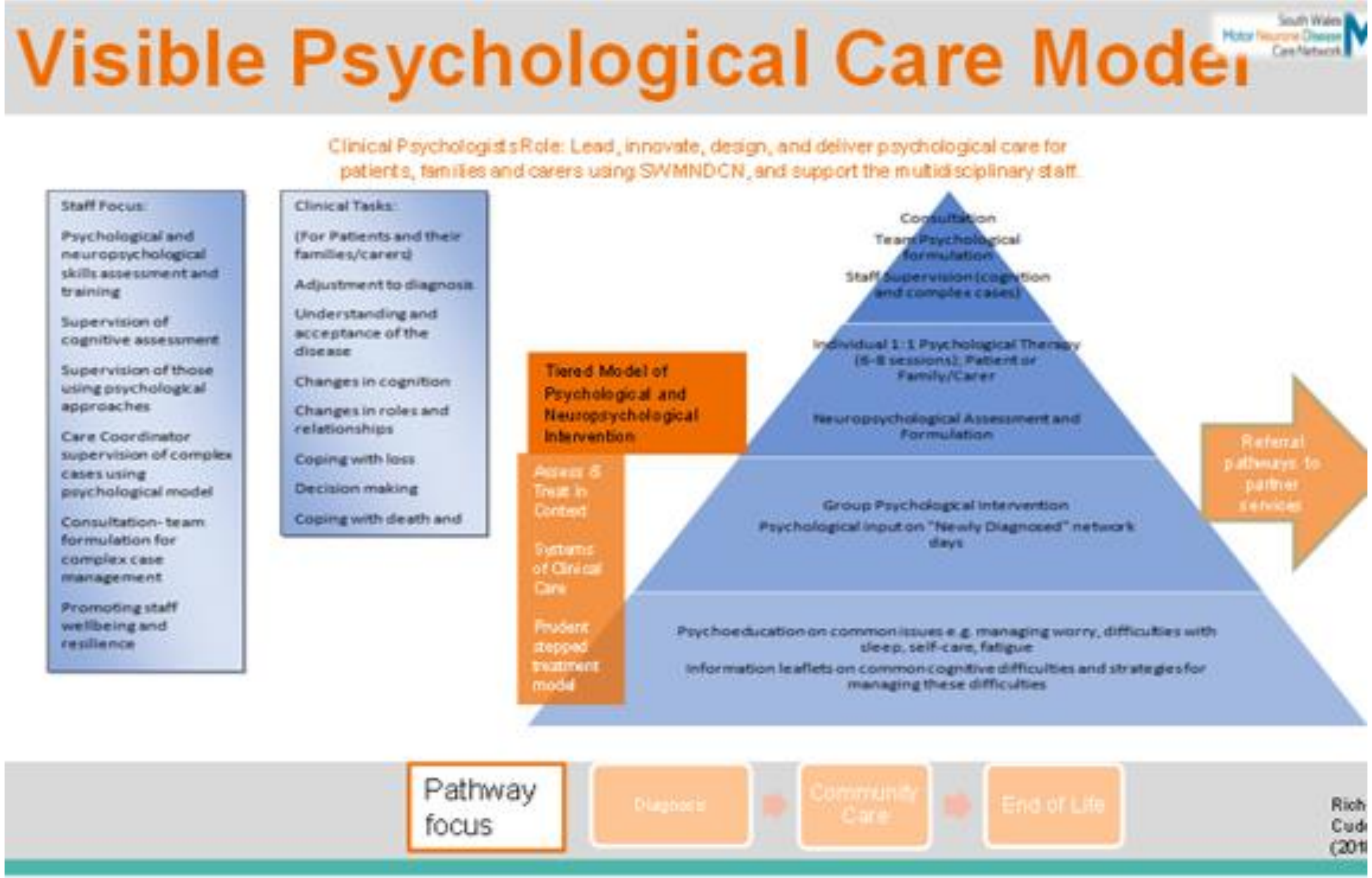
(Mujica-Mota et al, 2018)

EMBEDDING PSYCHOLOGICAL CARE WITHIN SERVICES

- The project report for South Wales (Hocking, 2020) recommended the need for a sustainable, quality-driven psychological model of care to be provided equitably across South Wales for patients with MND and their families, in line with the integrated approach seen in other neurological conditions and NICE guidance (2016).

- MND NICE guidelines do not currently offer any recommendations for how to deliver care, and the role of Clinical Psychologists working in MND across UK in posts funded by the MND association have evolved differently based on the local service set-ups.

- Therefore, some services focus on providing specialist support to PLW MND and their carers, whereas others focus on supervision, training, and support to other professionals; and where staffing resources allow, specialist MND Psychologists may work across all these levels.



Visible Psychological Care Model

South Wales Motor Neurone Disease Care Network

Clinical Psychologists Role: Lead, innovate, design, and deliver psychological care for patients, families and carers using SWMNDCN, and support the multidisciplinary staff.

Staff Focus:

- Psychological and neuropsychological skills assessment and training
- Supervision of cognitive assessment
- Supervision of those using psychological approaches
- Care Coordinator supervision of complex cases using psychological model
- Consultation- team formulation for complex case management
- Promoting staff wellbeing and resilience

Clinical Tasks:

(For Patients and their families/carers)

- Adjustment to diagnosis
- Understanding and acceptance of the disease
- Changes in cognition
- Changes in roles and relationships
- Coping with loss
- Decision making
- Coping with death and

Tiered Model of Psychological and Neuropsychological Intervention

- Assess & Treat in Context
- Systems of Clinical Care
- Prudent stepped treatment model

Consultation

Team Psychological formulation

Staff Supervision (cognition and complex cases)

Individual 1:1 Psychological Therapy (6-8 sessions): Patient or Family/Carer

Neuropsychological Assessment and Formulation

Group Psychological Intervention

Psychological input on "Newly Diagnosed" network days

Psychoeducation on common issues e.g. managing worry, difficulties with sleep, self-care, fatigue

Information leaflets on common cognitive difficulties and strategies for managing these difficulties

Referral pathways to partner services

Pathway focus

Diagnosis → Community Care → End of Life

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THE FUTURE

Research…and hopefully sustainable funding!

- iDeliver MND: Improving Delivery of Psychological Care in MND (Dr Emily Mayberry, Prof Chris McDermott, Dr Elizabeth Coates, Dr Sian Hocking)
- Healthcare research grant funded by MND Association- to explore and improve the delivery of psychological care for people living with and affected by MND across the UK.
  - Aim: "to identify what is important for MND psychology services to deliver, how this care is being delivered, funded, and evaluated, what is working well, and what can be improved. Based on the findings, we aim to develop recommendations about how best to set up MND psychology services to provide the care people need. This information can be used to update relevant guidelines and to make a stronger case to funders about the value of this work."

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