Providing Individual Tailored Support For Patients With Motor Neurone Disease And Their Families: The Impact Of a New Key Worker Role

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Background:

Motor Neurone Disease (MND) is a progressive terminal neurodegenerative condition, with six people diagnosed every day in the UK.[1] Its rapid progression & deterioration mean care needs to be carefully planned & targeted in a timely manner. Multi-Disciplinary Team (MDT) involvement is known to be beneficial for people living with MND. [2,3]

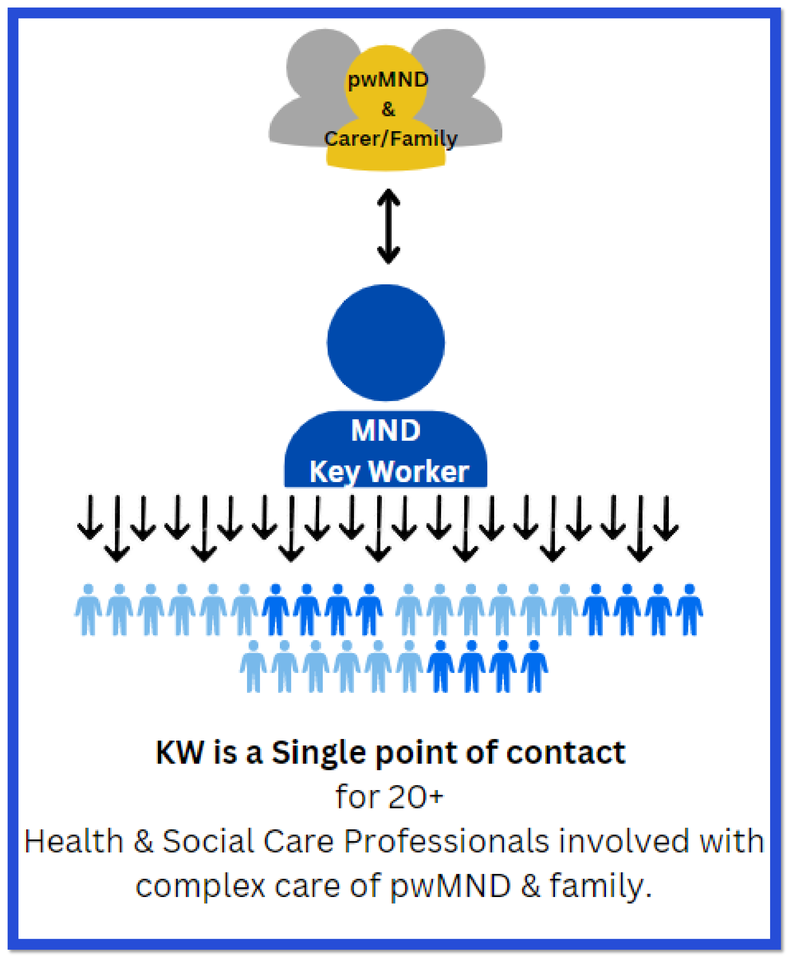
In the North West of England a consultation exercise with families & carers, identified a significant need for improved targeted and timely support. To address this a dedicated Key worker role was established to support patients and their families. The new service, referred to as the MND Key Worker (KW) project. was initially funded for two years with two elements: MND KW post (0.4WTE Band 6) and Psychological support (0.1WTE Band 6). An independent evaluation was commissioned to assess the impact of the new service.

Methods of independent evaluation of new Key Worker service:

The evaluation had a longitudinal, mixed-method design, drawing upon the methodology of evaluation research[4].

Data collection period: April 2021 to September 2022

- Audit data from the hospice
- Semi-structured interviews with: pwMND / carers (n=25) Key stakeholders (n=14)
- Two online surveys with internal and external stakeholders:
  - Survey 1 (n=24)
  - Survey 2 (n=27)



Example of impact of KW on pwMND & family:

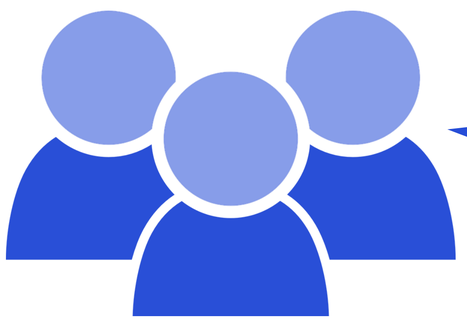
Interview with carer (son). Mother lives alone. Diagnosed with MND March 2020.

Son who works F/T reports KW provides essential support with the 'minefield' of liaisons with:
- Physiotherapist
- Occupational Therapists
- MNDA (assists with grants)
- Obtaining assistive equipment
- Pursuing health care reviews

Advance Care Planning

"So the sensitive bits that families don't often want to talk about [KW] can be more neutral on that, It is a really good benefit...

with her experience and with having a slight detachment it makes it a more logical process than an emotional one, perhaps".



"I'll go as far as to say literally an essential role because like I said, that is. To have one direct face to face that's a constant, I think it's **priceless**."

Reassurance

"So I mean if there was a real big breakdown in the package that's provided to my mum, I know one phone call to [KW] and I know that she would be on the phones to sort a care package."

Personalised care

"[KW] been instrumental with advice to me, she's been out and met mum face to face… because of mum's condition, as you can imagine friends and all the rest of it disappeared because of the lack of communication...

she [KW] goes out of her way to adapt, whether it be pen, paper, iPad or even understanding what speech mum can say."

Example of impact of KW on Professionals:

Quality of Support

"Excellent support offered with an extremely difficult social situation for a gentleman with MND recently."

(GP)

Value of Specialised Knowledge

"Provision of relevant information around MND (from significant experience understanding) to inform decision making.

Joint meetings held with regards to cases actions with specific action outcomes delivered by KW, as well as successful strategic discussion to inform managing communication & outcomes with partner agencies i.e. the Council."

(Adaptation Service Manager, Council)

Summary of Results:

Increase in pwMND & carers using hospice services including counselling. The evaluation has provided evidence that the KW is meeting its primary objectives & outcomes for pwMND and their families to provide:
- pwMND and their carers a single local point of contact
- Access into additional services provided by hospice
- Opportunities for social & community interaction
- Improvement in professional liaison.
- Provision of professional education sessions

There are several areas that still require further development:
- Professional liaison with MND Specialist Centre Staff
- Wider membership of MDT
- Wider support for Advance Care Plan conversations

Risk factors associated with the continuation of the project:
- High risk of a service run by single person
- Lack of time resource for the role
- Continuing lack of awareness of role in external professionals

Conclusion:

Data analysis indicates the introduction of a dedicated Key worker post to be beneficial to people with MND and their families.

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References
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