Challenges and Rewards of Setting up a Network Model – The Process of Setting up the South Wales Motor Neurone Disease (MND) Care Network

R. Glew, K. Gibbon, J. James, Dr K. Dawson, Dr I. Baker, Dr S. Hadjikoutis
South Wales MND Care Network, Morriston Hospital, Swansea/Rookwood Hospital, Cardiff, Wales

THE PROCESS

Ascertain pwMND
- SE Wales former care centre Database.
- SW Wales - MDT’s and searching consultant neurology letters.

Identify Problem Areas
Register areas of good and poor care, patient compliment and complaint.
Main problem areas identified:
- Inequity of access to NIV and cough Assist.
- Timely and appropriate decisions and action on gastrostomy tubes.
- Access to equipment and adaptations.

Establish and Maintain Links with professionals
- Contact existing primary and secondary health care teams and social service teams across 6 local health boards.
- Educational events.

Baseline Audit
January 2013
(See poster P125)

Establish Multi-disciplinary teams (MDT’s)
- Terms of reference.
- Patient review.
- Operational issues.
- Audit.
- MND Association links.
- Education.

Establish MDT Clinics
- 5 pwMND seen per clinic.
- 3 monthly review.
- Standardised assessment.
- Proformas to communicate care plan to primary care teams.

Education
- Education days:
  • Introduction to MND.
  • Advanced therapy in MND.
  • Palliative medicine and MND.
  - Training for social service professionals and support workers.
  - Training for allied health professionals.

Education study day Nov 2013
Carmarthen team members

Challenges
- Familiarising with and negotiating differing service configurations across all health boards and social services providers.
- Engaging and up-skilling health and social service staff.
- Practical considerations of clinics with multiple staff and patients.
- Negotiating input to clinics with service managers.

Rewards
- Satisfaction of providing holistic seamless and integrated patient care.
- Efficient, effective and timely care.
- Better access to information and support for pwMND.
- Positive feedback from pwMND and professionals.
- Better peer support.
- More effective communication between professionals.

By using local services team members bring differing knowledge and skills allowing for cross fertilisation of ideas between clinics which feeds development of the network. The network has excellent links with local MND Association branches and Association Visitors which enhances development of the network.

Conclusion
The Network approach to providing care for pwMND including engagement and motivation of local health and social service professionals and enthusiastic network staff can be helpful and rewarding with many benefits for pwMND, their families and professionals.

"Now at the new clinic, I see a range of specialists who see how well I am coping and look for early warnings that the disease is progressing.... The team is genuinely interested in my case.... As well as my health we address how things are at home and if any changes need to be made to help me manage.... We talk about what I think I need to continue to manage and things to consider for the future..... It is a very proactive approach and even if I feel I am coping, the team may still be able to suggest ways to make life easier."

"My appointments with the neurology consultant lasted about five minutes and would just check if my condition had changed."

And Now...