Motor Neurone Disease Association Tracking Survey

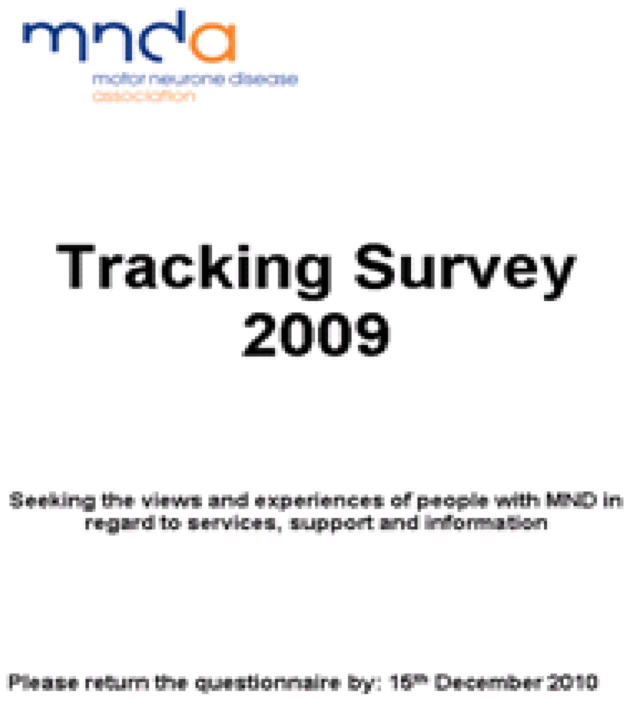
Karen Pearce

Director Regional Care (South)

motor neurone disease association

Do we do what our members want or expect?

The Tracking Survey - history



Tracking Survey
2009

Seeking the views and experiences of people with MND in regard to services, support and information

Please return the questionnaire by: 15th December 2010

- 8 surveys
  (1995 – 2009)
- 1 purely for carers (2003)
- 2 mixed group
  (1995 & 1998)

Why survey?

- Views from people living with MND
- Is the Association making a difference?
- Informs service development
- Informs strategic planning

→ Improved standards of care

Methodology

2005

- Association contact
- 2281 questionnaires
- 40% response rate
- Structured questions
- Free text

2009

(reported 2010)

- Association contact
- 1109 questionnaires
- 43% response rate
- Structured questions
- Free text

Questionnaire construct

- Personal details
- Diagnosis of MND
- After diagnosis
- Views on statutory services
- Equipment
- Benefits & funding
- Services MND Association provide

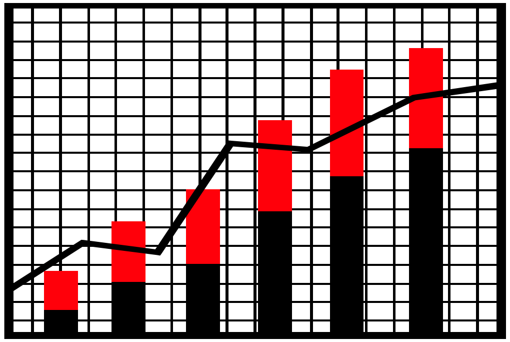
mnda
motor neurone disease
association

And key questions….

- End of life discussions
- Information about advanced decisions
- Making advanced decisions/directives

Important for future surveys

Sample reliability



- **Mean age 65 years**
- **63% male**
- **4% family history**
- **52% respiratory problems**
- **17% cognitive problems**

  Consistent with the literature

- **2% reported from BME groups**

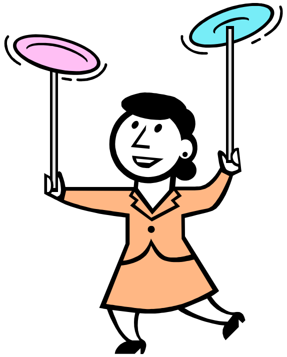
Results – no surprises here!

Top 6 results consistent since 1995

1. **Research**
2. **Care and support**
3. **Education of professionals**
4. **Public and political awareness**
5. **Taking part in research**
6. **Lobbying health providers**

What is news

- Seen by neurologist more quickly
- 29% > 6 months to diagnosis
- 75% patients heard of MND
- 34% not told about Association
- 25% did not have coordinated care



mnda
motor neurone disease
association

More news….

- Access to services
  - – Palliative care
  - – Out of hours
  - – Physiotherapy
  - – Respite care

- Advanced decision to refuse treatment
  - – 25% had not, but would like to

mnda
motor neurone disease
association

The Associations services

Demands increased dramatically

- Contributes to 24% equipment
- Contributes to 12% adaptations
- 44% use MND Connect
- 82% use leaflets
- 67% equipment loan

No reduction in standards

Key action areas

- **End of life issues: development of national standards (NICE)**
- **Awareness raising: clinical lead appointment with RCGP**
- **Independence: national wheelchair delivery model**

motor neurone disease association

In Summary

The survey shows that the MND Association is doing a good job and is in tune with its members…….

However, constant monitoring of the health and social care environment and the experiences of people with MND must continue if this is to remain so.

mnda
motor neurone disease association

Thank You!

Any questions

mnda
motor neurone disease
association