

# Living and Dying with MS in Newcastle upon Tyne

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## Introduction

The City of Newcastle upon Tyne has a population of approximately 260 000 (1) with an estimated prevalence of people with MS (pwMS) of between 260 – 364 (2).

The CMST is a multi-disciplinary, cross agency team that was set up to provide comprehensive health and social care for pwMS and their families within the locale of Newcastle upon Tyne.

At any one time the CMST have a case load slightly higher than predicted prevalence of approximately 400 pwMS, we therefore infer that most pwMS living in the City of Newcastle are known to the team.

This poster reports on the findings of a recent clinical audit, highlighting data the CMST have collected over a 12-year period with regard to age of pwMS at the time of death.



## Aim of Audit

Authors suggest that life expectancy in pwMS is shortened by only 5 – 10 years (2). However the clinical experience of the team has been that once a pwMS has entered the progressive stage of the disease process their life expectancy is significantly shortened.

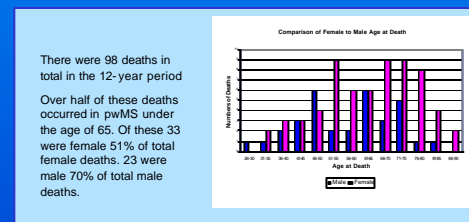
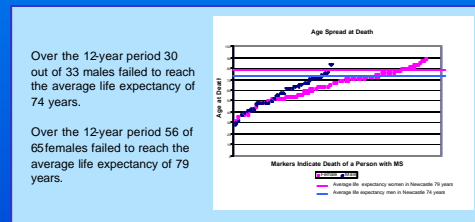
The audit aimed to explore the local picture with respect to life expectancy utilising routinely collected data. Ultimately it is hoped that the audit data will help to inform clinical and strategic planning for the CMST.

## Results

98 people with a clinical diagnosis of MS are included in this audit with an approximate female to male ratio of 2:1 (65 female, 33 male).

Average life expectancy for men in Newcastle is age 74 years (3) but in MS population known to the CMST the average age at death has been 56.6 years i.e. approximately 17 years 5 months less than their male peers. Over the 12-year period only 3 males achieved/exceeded the average life expectancy of 74.

Average life expectancy for women in Newcastle is age 79 years (3); again in our known MS population the average age at death has been lower at 62.9 years i.e. approximately 16 years earlier than their female peers. Over the 12-year period 9 females achieved/exceeded the average life expectancy.



## Discussion

The audit data suggests that life expectancy in pwMS in this area is lower than research would suggest. **This implies that:**

- We may be misinforming people newly diagnosed with MS
- We may not be as successful as research suggests in reducing premature deaths by improving health care (4)

**However:**

- The audit data collected looks at pwMS who have died over the last 12 years and doesn't provide information on pwMS in Newcastle upon Tyne who are still living and may achieve or exceed their average life expectancy.
- We need to examine further the causes of death as cited on death certificates in order to investigate the frequency with which MS is entered as a primary or secondary cause of death.

## Conclusion

The data collected highlights a potential need for the issue of life expectancy with a diagnosis of MS to be reviewed. It has raised implications for how the CMST works:

- We must ensure that we are being proactive and timely with interventions, especially those linked to later stages of MS and palliative care.
- We should evaluate our therapeutic interventions in the light of cause of death data, e.g. chest care in advanced MS, to endeavour to achieve more positive outcomes.
- We need to ensure that we give due regard to end of life care and future care planning, supporting and caring for both pwMS and their families:

"Promoting high quality care for all adults at the end of life 'How people die remains in the memory of those who live on' Dame Cicely Saunders, founder of the Modern Hospice Movement" (5)

## References

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2. Compston, A. et al (eds) (2006) Section two: The cause and course of Multiple Sclerosis. In McAlpine's MS Fourth ed. Philadelphia Churchill Livingstone
3. Office for National Statistics (2007) Office for National Statistics Neighbourhood statistics. Area: Newcastle upon Tyne (Local Authority) Life expectancy: Health and disability-free years 2001 [http://www.neighbourhood-statistics.gov.uk/discussion/07\\_eadt/TabId/1064](http://www.neighbourhood-statistics.gov.uk/discussion/07_eadt/TabId/1064) (accessed 28<sup>th</sup> July 2008)
4. [www.mssociety.org.uk/about\\_ms/next\\_questions/llife\\_expectancy.html](http://www.mssociety.org.uk/about_ms/next_questions/llife_expectancy.html) (accessed 2nd October 2008)
5. Department of Health. End of Life Care Strategy (July 2008)