

# The cost of Muscular Dystrophy

Report by Access Economics Pty Limited for the

**Muscular Dystrophy Association**



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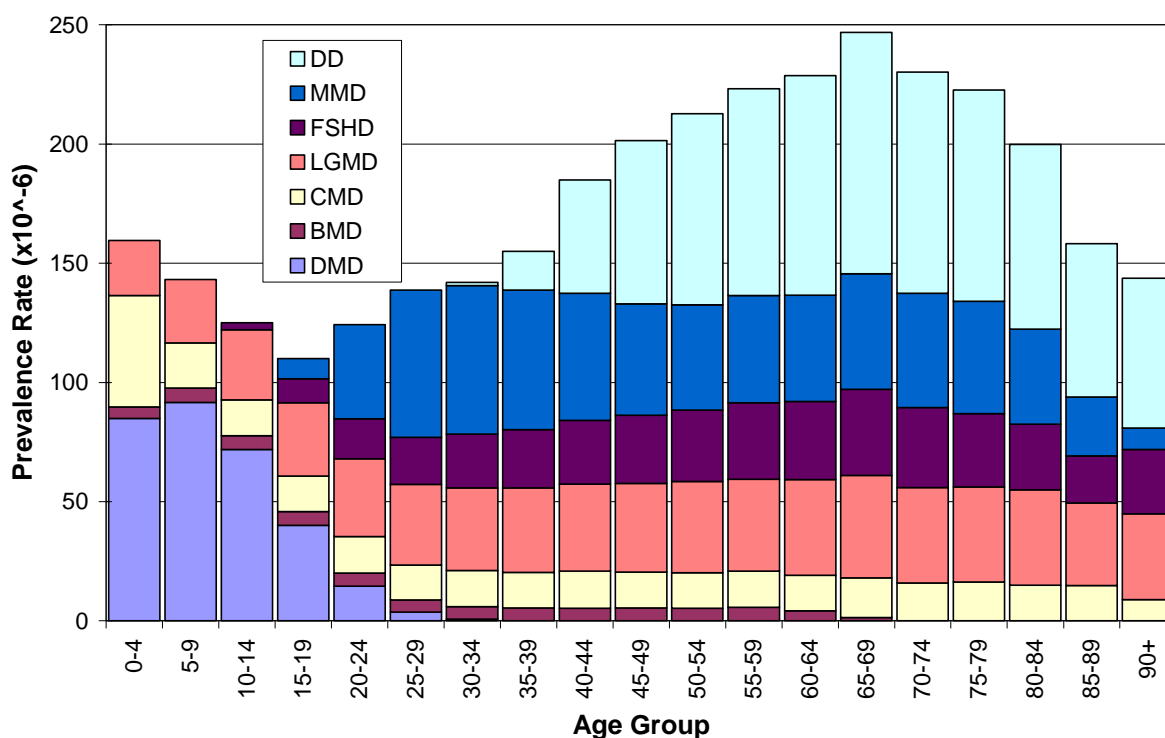
## EXECUTIVE SUMMARY

Muscular Dystrophy (MD) is the name given to a group of genetic and hereditary muscle neuromuscular diseases characterised by progressive weakness and degeneration of the skeletal muscles that control movement. The various forms of MD differ in terms of the extent and distribution of muscle weakness, age of onset, rate of progression and inheritance pattern.

### MD in Australia

The main forms of MD included in this analysis are Duchenne (DMD), Becker (BMD), Congenital (CMD), Limb-Girdle (LGMD), FacioScapuloHumeral (FSHD), Myotonic (MMD) and Distal (DD). Access Economics used a meta-analysis of prevalence rates from the international literature to estimate the prevalence of these forms of MD in Australia, with results shown below. Overall, 170 Australians in a million will have MD.

**PREVALENCE RATE OF ALL MD TYPES, 2005 (RATE PER MILLION)**



In total, there are an estimated 3,457 Australians with MD; 56% of people with MD are male, although 82% of children aged 0-14 years with MD are boys. Most people with MD have DD, LGMD or MMD, which together include more than 60% of all Australians with MD.

- Two thirds of people with MD are working age (15-64 years) with a further 16% aged under 15 years.

Morbidity and mortality from MD include pulmonary complications, cardiac involvement and mental retardation. The relative risk of mortality for MD is very high (424 times the population risk for males and 149 times for females), with 290 deaths from MD estimated in 2005.

- Of these deaths, 133 (35%) were children aged under 15 years.

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## Costs of MD

In 2005, the **financial cost of MD was \$435 million**. Of this:

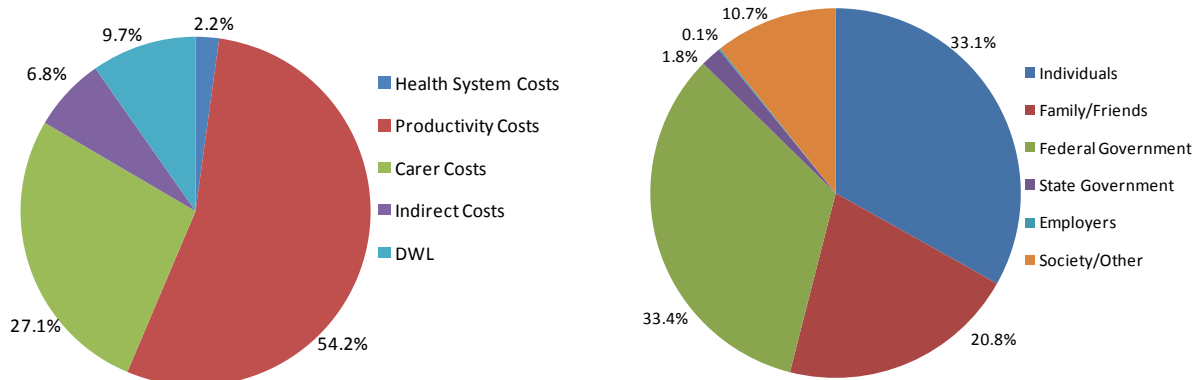
- ❑ \$236.2 million (54.2%) was productivity lost due to lower employment, absenteeism and premature death of Australians with MD;
- ❑ \$117.8 million (27.1%) was the value of the informal care for people with MD, provided by parents and other close family or friends;
- ❑ \$42.4 million (9.7%) was the deadweight loss from transfers including welfare payments (mainly Disability Support Pension and Carer Payment) and taxation forgone;
- ❑ \$29.7 million (6.8%) was other indirect costs such as aids and home modifications, formal care services, transport and the bring-forward of funeral costs; and
- ❑ \$7.4 million (2.2%) was the direct health system expenditure.

Additionally, **the value of the lost wellbeing (disability and premature death) was a further \$1 billion**.

In per capita terms, this amounts to a **financial cost of around \$126,000 per person with MD** per annum. Including the value of lost wellbeing, the cost is over \$415,000 per person per annum.

Individuals with MD bear one third of the financial costs, and their families and friends bear a further 21%. Federal government also bears one third of the financial costs (mainly through taxation revenues foregone and welfare payments). State governments bear under 2% of the costs, with the remaining 11% borne by others in society (including employers). If the burden of disease (lost wellbeing) is included, individuals bear 80% of the costs.

**FINANCIAL COSTS OF MD, BY TYPE OF COST AND BY BEARER (% TOTAL)**

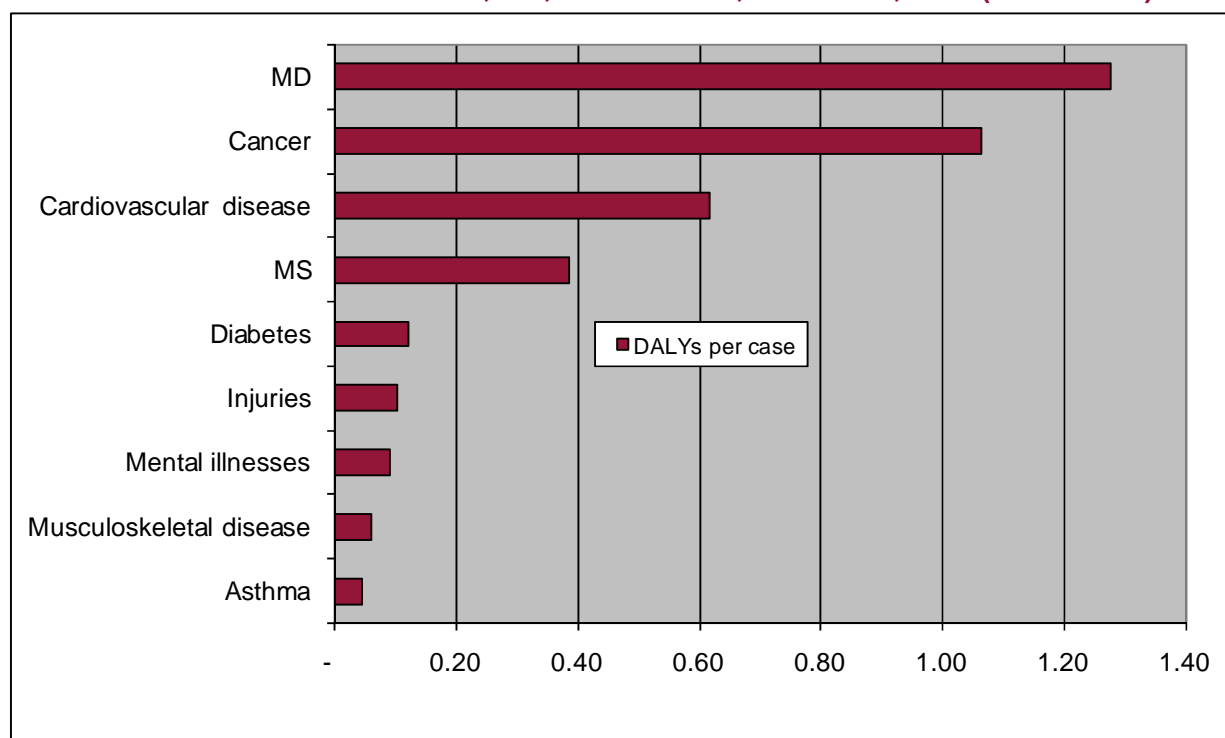


Compared to other health conditions, MD is:

- ❑ relatively low in prevalence and health system expenditures, with only around 0.01% of total health expenditures;
- ❑ very high in its indirect costs, much higher per capita than most other health conditions studied by Access Economics, largely due to the younger onset and high mortality of children with MD, which reduces productive capacity and increases the need for resource directed towards care; and

- has a similarly substantial burden of disease, with over 2 Disability Adjusted Life Years (DALYs) lost for every year that a person has MD; again, this is high relative to other health conditions to the substantial mortality component of MD.
  - Even using the lower Australian Institute of Health and Welfare (AIHW) burden of disease data, the high case burden of MD relative to other national health priority areas (NHPAs) and to multiple sclerosis (MS) is evident, as illustrated below, which shows the DALYs per case for MD higher than for any other NHPA and higher than for MS.

### COMPARISON OF CASE BURDEN, MD, MS & NHPAs, AUSTRALIA, 2003 (DALY/CASE)



Source: Access Economics based on data from Begg et al (2007). Note: prevalence data are used for cases wherever these are available in the publication; otherwise incidence data are used.

A final consideration is that, if the cost per person of all neuromuscular disease is similar to the cost per person for MD, then the cost of of neuromuscular diseases may be around four times these cost estimates for MD alone.

### Future directions

The analysis in this report underscores that lifetime costs are higher for conditions with onset earlier in life. To this end, the following strategies are recommended.

- **Research:** There is a need for more research into the 'cause, care and cure' of MD, given current knowledge limitations and the scope for future gains.
  - Commissioning the first ever Australian longitudinal, epidemiological study of MD could correct data gaps that are a major limitation to understanding the incidence, prevalence, mortality, comorbidity, trends and issues for the different forms of MD.
  - A national neurological research centre could help redress the current imbalance in research financing and help attract good researchers to work in neurology.
  - Greater understanding of the genetic transmission of inherited forms of MD may assist with earlier identification and intervention.

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- ❑ **Diagnosis and early intervention:** Education and support programs for mainstream primary care, peri and post-natal services are important to assist with earlier differential diagnosis, to reduce misdiagnosis and to reduce the long lags between onset of symptoms and treatment with provision of intervention services.
- ❑ **Health service delivery issues:** There is a need to better address the pulmonary and cardiac complications of MD through mechanisms such as non-invasive ventilatory support. Other core issues to address are:
  - ongoing, timely access to appropriate medications including corticosteroids and specific treatments for MMD;
  - timely access to orthopaedic surgical procedures in public hospitals to correct complications such as scoliosis and spinal fusion;
  - timely access to physiotherapy and orthotic and general counselling services through public hospital outpatient departments and other community programs.
- ❑ **Employment initiatives:** Employment programs are required to enhance employment opportunities, retention and adaptation of existing jobs for people with MD and other chronic disabling illnesses, including innovative strategies such as extension of employer incentive schemes, job restructuring or tailoring, part-time and flexible work-from-home options, and transport assistance, as appropriate, together with awareness strategies to counter workplace misperceptions and discrimination.
- ❑ **Policies to assist carers:** Design and delivery of extended relevant support, education and respite services to assist the large proportion of people with MD who are profoundly disabled and live at home, with informal care provided by parents and other family members, with an emphasis on employment continuity for carers.
- ❑ **Appropriate accommodation:** There is a shortage of age-appropriate day care and longer term disability housing for young people with MD. Alternative and better coordinated models of care need to be established across the Commonwealth and State jurisdictions to result in more seamless, flexible and multidisciplinary care and age-appropriate accommodation services.
- ❑ **Transport, aids and home modifications:** People with MD and their families and carers frequently require assistance with mobility, communication and other activities of daily living. Wheelchairs, walkers and splints, ramps, showering and bathing aids are still financed largely out of pocket by people with MD and their families and carers. Better access to assistance in these areas is necessary to address the unmet need and to provide reimbursement for large items in a timely manner.
- ❑ **Financing reforms:** Consideration needs to be given in the next election cycle (2007-2010) to methods for long term financing of health and disability care needs, in particular to devise ways of channelling private sector resources more effectively to enhance care and outcomes, including through purpose specific savings programs (such as Health Savings Accounts), access to preserved superannuation lump sums for younger people with disabilities, and Disability Trusts to fund accommodation and support services through public-private partnerships.
- ❑ **Disadvantaged groups:** It is recommended that MD services reflect the different needs of different groups of people, with equal and improved access for people with MD and their families and carers, in particular people who live in rural and remote regions of Australia and/or who are indigenous Australians or are from culturally and linguistically diverse backgrounds.

**Access Economics**  
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