

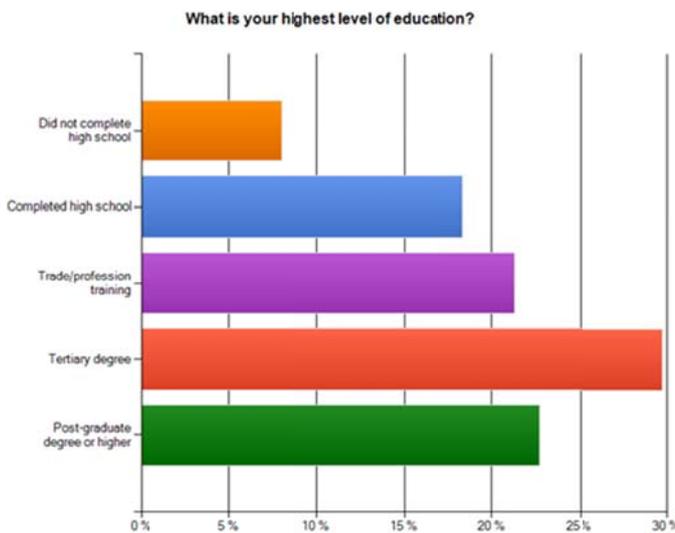
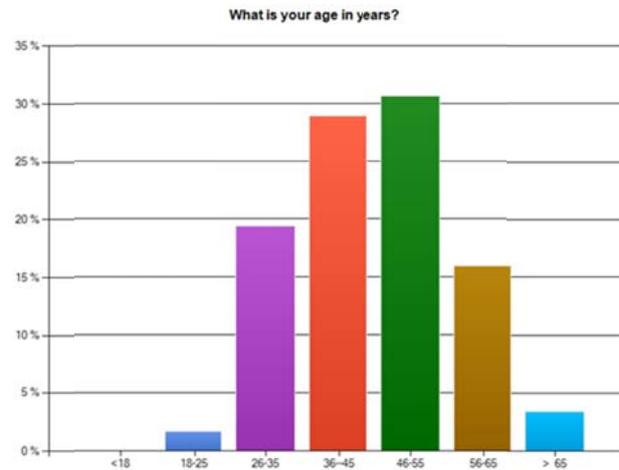
2012 MSAC Employment Survey Results – Full report with statistics

About you

A total of 414 people with MS took part in the survey: 21% were men and 79% were women.

Everyone was aged at least 18 years. Most were 26–65 years of age (see graph).

Most (77.8%) of the respondents lived in Victoria, but 8.7% of people were from NSW, 2.4% from the ACT, 9.7% from other parts of Australia, and 1.4% did not currently live in Australia



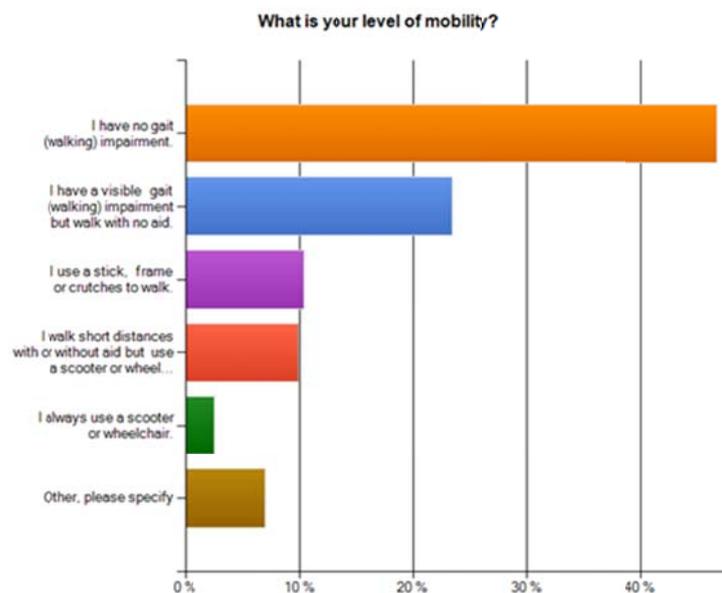
People living in different types of communities were well represented, including 58.9% living in a capital city, 19.8% in a major regional centre, 15% in a smaller town and 6.3% in a rural or remote area. This is consistent with Victorian data from the 2011 Australian Census showing 71.2% lived in a major urban centre, 18.6% lived in another urban location and 10.1% of the population lived in a rural area.

Respondents were highly educated: 52.4% had completed a tertiary degree (see graph) compared with 14.3% of Australians having a tertiary degree in the 2011 Census.

As expected, most (76.1%) respondents had relapsing remitting MS. 10.1% had secondary progressive MS, 7.7% had primary progressive MS and 6% were unsure or had another type of MS.

Overall, 45% of people were diagnosed with MS in the last 5 years. However, some respondents had been living with MS for much longer, including 1% diagnosed prior to 1980.

Most people had relatively good mobility, with almost half having no visible walking problem and fewer than 3% using a wheelchair or scooter all the time (see graph).

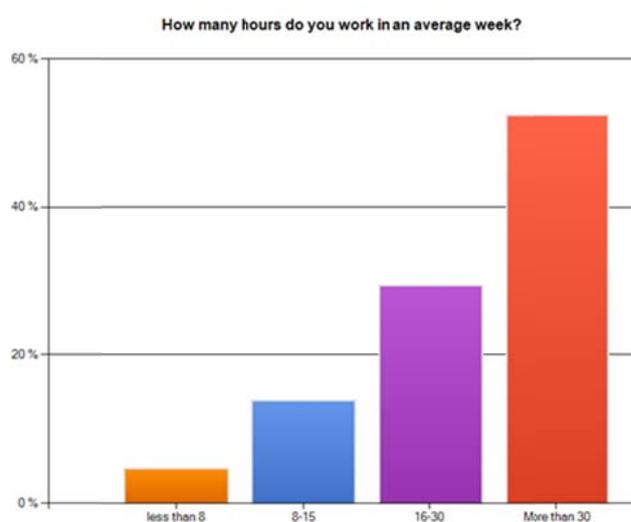
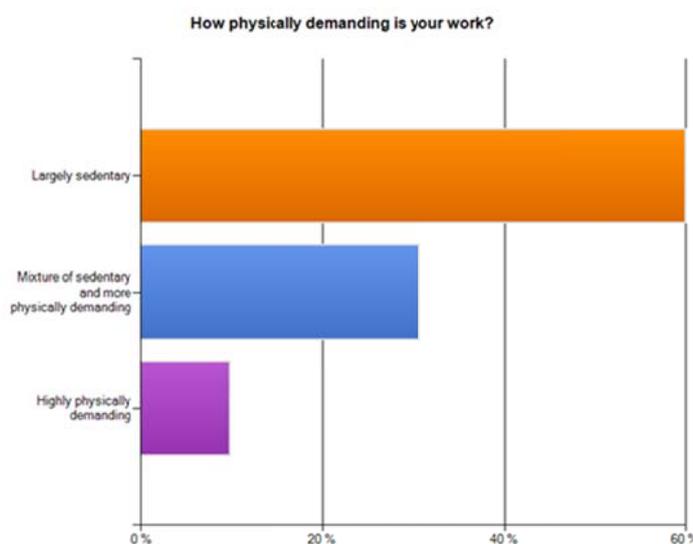


Employment information

People currently in paid employment

In total, 63.5% of people who took part in this survey were in paid employment. Of these people, 60% were involved in mainly sedentary work, but 9.5% described their work as highly physically demanding (see graph).

People were doing many different types of jobs including substantial numbers involved in each of education, administration, healthcare, finance, management, retail and IT.



Nearly half (47.7%) of respondents were working 30 or fewer hours in an average week (see graph). This compared with the 2011 Census data showing that among employed Australians aged >15 years

- 10.8% worked ≤15 hours per week
- 19.6% worked 16-34 hours per week
- 63.3% worked ≥35 hours per week.

Almost half of respondents (48.5%) had reduced their hours of work because of their MS symptoms, and 36.3% had changed their type of work because of their MS symptoms.

More than one in five (22.9%) people had changed both the amount *and* type of work they do because of their MS symptoms.

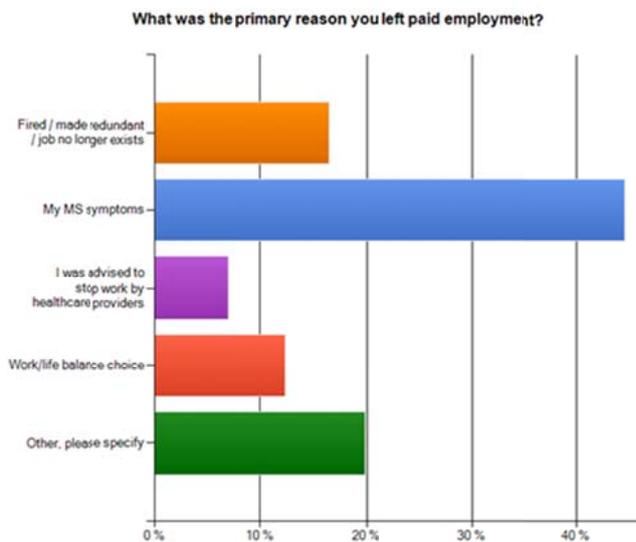
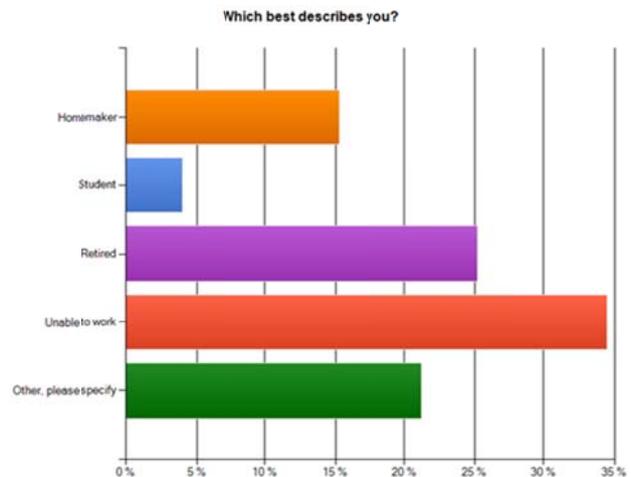
People NOT currently in paid employment

Approximately 36% of respondents were not in paid employment. According to the 2011 Australian Census, only 5.6% of Australians who considered themselves to be part of the workforce were unemployed.

Almost all of these people (97.4%) had previously been in paid employment.

Of those not currently employed, one third (34.3%) said they were now unable to work, 25.3% were retired, 15.2% were homemakers, 4% were students and 21% described their current role as “other” (see graph).

About two thirds (67.8%) of those who had previously worked said MS was a factor in their leaving paid employment.



MS was the *primary* reason that 44.5% of people had left paid employment, although others stopped paid work for a variety of reasons (see graph).

Most (80.8%) of those not currently working were not seeking paid employment. The reasons given were:

- Can't work due to MS (39.3%)
- Financially secure (16.4%)
- Given up finding work (10%)
- Other

Factors associated with being currently in paid employment

We were interested to know if any of the personal details (such as age, gender, place of residence, MS details) were associated with employment status. On univariate analysis (looking at one factor at a time) we saw no association between gender and employment status among people living with MS. However, some factors were strongly associated with employment status in this survey:

1. **Age: younger people were more likely to be employed.** 24 out of 80 participants aged over 55 years (30%) were employed versus 239 out of 334 participants aged 55 years or less (72%), $p < 0.001$, Chi square test. We saw evidence of consistently declining employment rates among people with MS with age. Employment rates in the various age categories were as follows: 18-25: 86%, 26-35: 79%, 36-45: 75%, 46-55: 63%, 56-65: 32%, >65: 21%
2. **Place of residence: people living in capital cities are more likely to be employed.** 173 out of 244 people living in a capital city (71%) were in paid employment, versus 90 out of 170 living in any other type of area (53%), $p < 0.001$, Chi square test. In general, there was only a modest difference in employment rates in large regional centres (56%), smaller towns (52%) and rural or remote areas (46%).
3. **Level of education: people who had a university degree were more likely to be employed than those without.** Overall, 102 of 197 (51.8%) people who had not completed a university degree were currently working, compared with 161 of 217 (74.2%) of those who had completed a university degree, $p < 0.001$, Chi square test. These figures remain true regardless of whether people had completed high school or not, had training in a trade, or had gone on to complete a post-graduate or higher degree.
4. **Mobility: people with better preserved mobility are more likely to be employed.** Among the 385 individuals who selected a specific level of gait impairment, there was a clear drop in employment rates as gait became more impaired. 81% of those with no gait impairment were employed, compared with 59% of those who had a visible gait impairment but use no aid, 40% of those who used a stick, walker or crutches, 34% of those who used a scooter or wheelchair for longer distances and 27% of those who used a wheelchair or scooter all the time. When we compare those with a visibly normal gait to all others (including those who selected "other") 81% of those with normal appearing walking were employed, compared with just 47% of the other groups - a highly significant difference; $p < 0.001$, Chi square test.
5. **Type of MS: those with relapsing remitting MS are more likely to be employed than those with other types.** 224 of 315 (71%) people with relapsing remitting MS were employed, compared with 39 of 99 (39%) of those with any other type of MS, $p < 0.001$, Chi square test.
6. **Time living with MS: people were more likely to be employed if they were diagnosed with MS more recently.** Those who were in paid employment had been diagnosed with MS for a median of 5 years (range 1-34) whereas those NOT in paid employment had been diagnosed with MS for a median of 10 years (range 1-34 years), $p = 0.0001$, Wilcoxon rank sum test.

When we did multivariate analysis (taking into account all of the above factors simultaneously), the factors that were independently associated with being in paid employment among people with MS who participated in this survey were being aged 55 years or younger, having a visibly normal gait, having a university degree and living in a capital city (see Table for details).

Table: Factors independently associated with currently being in paid employment in this survey. Logistic regression modelling: model $p < 0.0001$ and model $R^2 = 0.19$

Variable	Odds ratio	95% CI	p value
Age ≤ 55 years	4.3	2.4 - 7.7	< 0.001
Having a visibly normal gait	3.7	2.3 - 6.0	< 0.001
Having a university degree	2.4	1.5 - 3.9	< 0.001
Living in a capital city	2.3	1.4 - 3.5	0.001

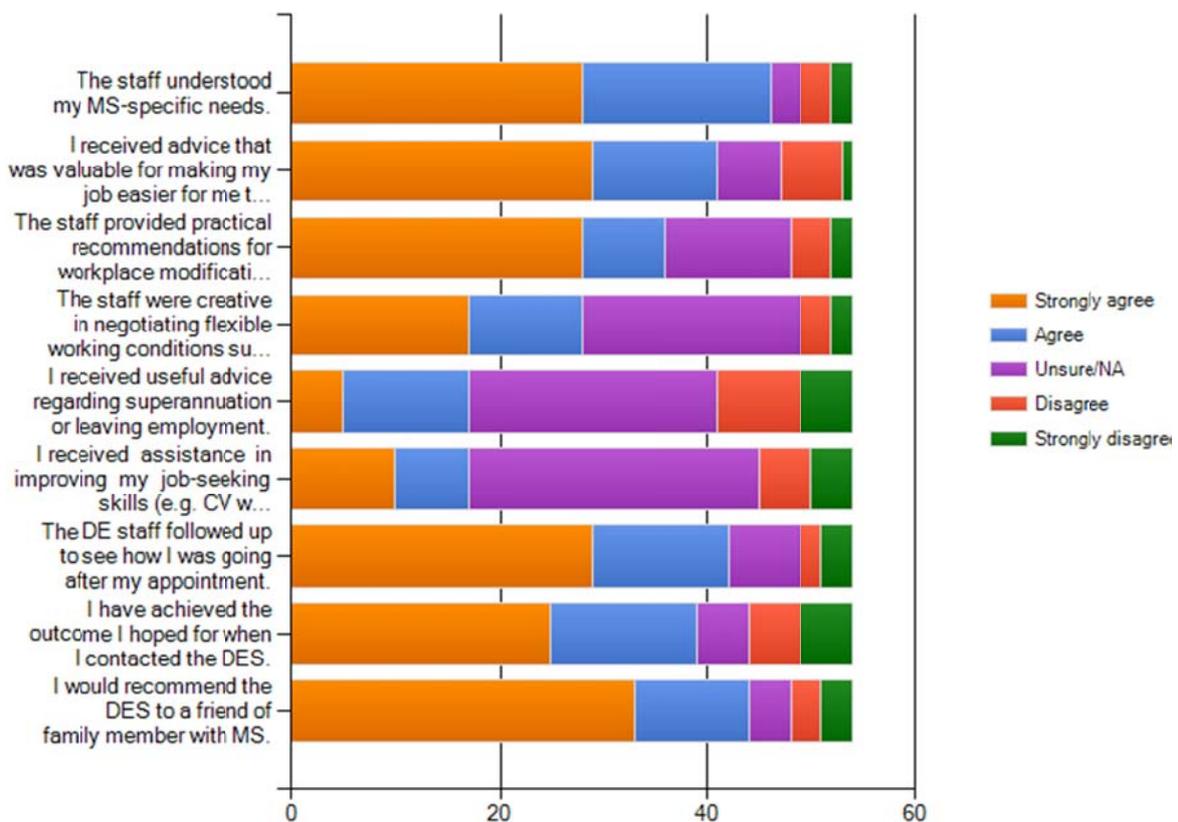
Knowledge and experience of Disability Employment Services (DESS)

Of the people currently working or seeking paid employment, 290 answered questions about their knowledge and experience of DESS.

Fewer than half (49.7%) had heard of a DES. Only one in five (19.7%) had ever visited a DES. In most (80.4%) cases, they had done so within the last 12 months.

Views of people who had visited a DES

People were asked to rate their level of agreement (from strongly agree to strongly disagree) with several statements about their experience of visiting a DES. As can be seen from the chart below, there was a wide variety of experiences, although a large percentage felt the staff understood their MS-specific needs and would recommend the DES to a friend or family member with MS.



The three statements people were *least* likely to agree or strongly agree with were:

- I received useful advice regarding superannuation or leaving employment.
- I received assistance in improving my job-seeking skills (e.g. CV writing, interview skills).
- The staff were creative in negotiating flexible working conditions suitable to my needs.

People who were in paid employment when they visited the DES (62.5%) were more likely to agree or strongly agree with the statements “I have achieved the outcome I hoped for when I contacted the DES” ($p=0.01$, Fisher’s exact test) and “I would recommend the DES to a friend of family member with MS” ($p=0.04$, Fisher’s exact test) than those who were not employed at the time of their visit.

When asked what they consider to be the three most important services a DES can offer, almost half of the respondents who had visited a DES selected “Assistance with negotiating flexible working conditions”.

Responses to “What did the DES do especially well” and “What could the DES have done to meet your needs better” are shown in the Appendix.

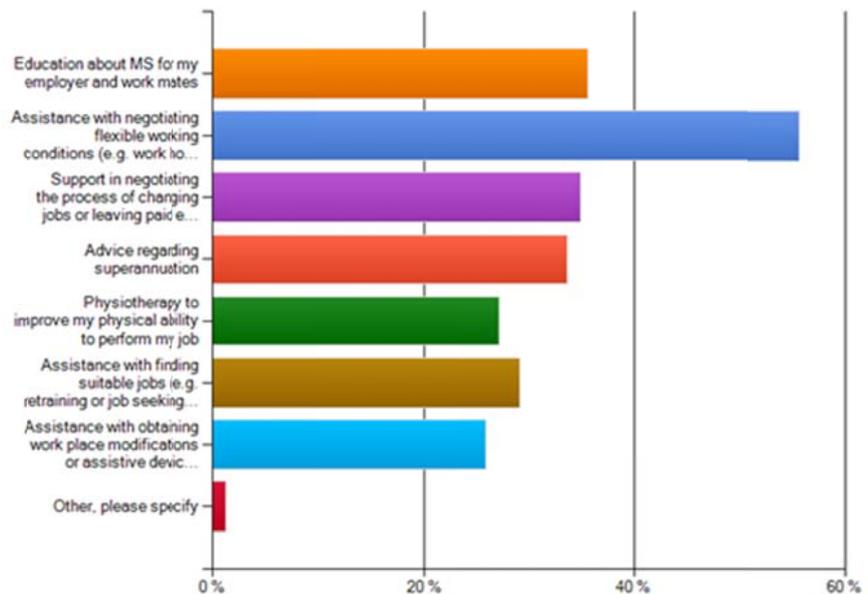
Views of people who have never visited a DES

It was interesting to note that two thirds of people (67.7%) stated they would consider visiting a DES, including 100 who had not previously been aware that these services existed.

When asked to rate how highly they would value a list of possible services a DES might offer, most people ranked everything on the list very highly:

- Education about MS for my employer and work mates
- Assistance with negotiating flexible working conditions
- Assistance with obtaining workplace modifications / assistive devices
- Support in negotiating the process of leaving paid employment
- Advice regarding superannuation
- Physiotherapy to improve my physical ability to do my job
- Assistance with finding suitable work.

When people were asked to choose the three services they thought would be *most* valuable from a DES, the service valued by most people was “Assistance with negotiating flexible working conditions.” (see graph). This was also one of the most popular choices among those who had previously visited a DES.



Conclusions

1. In this survey, being currently involved in paid employment was associated with younger age, better mobility, having a university education and living in a capital city.
2. Most people who were not currently employed had been in paid work in the past.
3. Many people who were not currently employed were not seeking paid work, often because their MS symptoms prevented them from working.
4. Fewer than half of the survey respondents had heard of a DES, but many stated they would consider visiting a DES now that they knew they existed.
5. Although only a small proportion of people with MS who were employed or seeking employment had visited a DES, most of those who had used one of these services had found it to be valuable.
6. The experience of visiting a DES was most useful to those who were employed at the time they used the service.
7. The service rated most valuable by people with MS, whether or not they had visited a DES, was assistance with negotiating flexible working conditions. Those who had used a DES often felt this was not done optimally.

Based on these findings, we recommend that DES awareness needs to be improved among people living with MS. This is a particular priority among those who are currently employed. Negotiating flexible working conditions is an area where DESs may be able to improve their service provision to better meet the needs of people with MS.