
**Background**
Loss of hand function is one of the major features of Rett syndrome. Video is ideally suited to capturing daily function from anywhere in Australia and to show function in everyday settings. Therefore, we used video data to examine changes in hand function over time. We also investigated what other factors might influence these changes.

**What we did**
We collected videos from families participating in the Australian Rett Syndrome Study. This was done in 2004 and again in 2007/2008. We observed the hand function of the girls and women in the videos and classified them into different levels. We then looked at the changes in the levels of hand function over time and compared these changes by MECP2 mutation type, age group and the ability to walk.

**What we found**
Comparing the hand function shown in both videos, we found that over the intervening 3 to 4 year period, approximately 60% of the girls who showed some hand function during the first video maintained their skills on the second video. A few girls improved and approximately 40% lost some skills. Those with the highest and lowest levels of hand function were less likely to experience changes in hand function over time.

Girls who were in their teenage years were less likely to lose hand function compared to younger girls. Those who were able to walk or had learned to finger feed were also less likely to lose their hand function.

**What does it mean**
Comparing changes in hand function over time has never been described in Rett syndrome before and it appears that hand function is a relatively stable aspect of daily function. There was considerable variability in the characteristics of who maintained skills. However in general, teenagers and girls/ women who could walk were a little more likely to maintain their hand
skills. The extra stimulation from these activities could help to maintain hand skills.

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