

## Q&A - Mortality and cause of death of Autistic Australians

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Recently, an Australian study found that Autistic people have double the “comparative mortality rate”, or death rate, of the general population. This sounds both alarming and potentially confusing.

### What was the study about?

This study compared the death rates of Autistic people with those in the general population. They also looked at the causes of death in Autistic people, and compared these with the general population.

It included information about nearly 36,000 Autistic people in NSW, and looked at all the people in this group who died from 2001 to 2015, between the ages of 5 and 64 years old.

### What does “comparative mortality” mean?

“Comparative mortality” compares the death rate in a particular group with the death rate of the general population, by looking at people who died at different ages.

In this study, Autistic people who had died between 2001 and 2015 were grouped according to their age (5-14, 15-24, 25-44 and 45-64 years). These numbers were compared with deaths in the general population to find out if Autistic people were more likely to die than people in the general population from 5-64 years of age inclusive.

### What did the study find?

The study found that Autistic people were twice as likely to die as the general population. Autistic people were most likely to die from injury or poisoning (including accident and suicide), while nervous system disorders such as epilepsy were the next most common cause of death. The general population, on the other hand, were most likely to die from cancer, or from diseases such as heart attack or stroke.

They also discovered that sex, distance from a city and wealth were **not** associated with increased likelihood of death in the Autistic population, which they are in the general population.

### **Does this mean I'm going to die early?**

No, not at all. It shows averages, but has no power to predict anything about the life or death of any individual Autistic person.

### **So why are Autistic people dying younger?**

It's hard to be sure, but the increased likelihood of death from injury or poisoning strongly suggests that Autistic people aren't getting their healthcare needs met.

Another factor is that Autistic people tend to have complex health needs, with more chronic illness. This may be because our healthcare needs aren't being met properly, or there may be other issues that we're not aware of yet.

### **What can we do about it?**

First, it's a good thing that we know about it. We also know that a lot of Autistic people have trouble when they use the health care system, and think that this might be part of the reason.

One thing that may help is better education for healthcare workers. If doctors and other healthcare workers understand what Autistic people need, Autistic people will be healthier, both physically and mentally.

We can also support Autistic people when they have to go to doctors and hospitals.

Finally, we will keep researching what the issues are, and as we learn more, we will be able to do more.

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