Information for patients from JNNP

Who is most likely to improve after treatment for Guillain-Barré syndrome?

What do we know already?
Guillain-Barré syndrome is a rare but serious condition that affects the nervous system, which controls your senses and your movements. If you have Guillain-Barré syndrome, your immune system, your body’s defence against infection and illness, attacks and damages your nerves. This leads to muscle weakness that can cause problems walking and moving your limbs, talking, breathing and controlling your stomach and bladder. Around 80 in 100 people with Guillain-Barré syndrome make a full recovery within a few weeks or months. But some people may take longer to recover, and doctors can’t be sure what’s likely to happen to people once they start treatment.

To find out more, researchers looked at 10 studies of more than 5,000 people with Guillain-Barré syndrome. In particular, they looked to see if there were certain things, called predictors, that meant people were more likely to do well and feel better if they had treatment for Guillain-Barré syndrome. They looked at what things predicted if, after treatment, people would:

- Be able to walk with or without help
- Be able to breathe without help from a machine
- Have their symptoms come back again within a year of starting treatment
- Be able to do everyday things like climb stairs, dress themselves, cut meat, or write a year after treatment
- Need to change jobs because of their illness a year after treatment
- Die within the first year after treatment.

What does the new study say?
Overall, after treatment for Guillain-Barré syndrome, around 4 in 100 people died. Around 20 in 100 people were able to walk without help after 4 weeks, and 80 in 100 people were able to walk without help after six months. Around 60 in 100 people got back their muscle strength after one year, while 14 in
100 people still had a disability after one year. Around 4 in 100 people who recovered had their symptoms come back in the first year. The researchers found that people who were older (particularly aged 50 and over), people who had weaker muscles, who were more disabled or who had diarrhoea were the most likely to do poorly, even after treatment for Guillain-Barré syndrome. People who had diarrhoea and people with muscle weakness were also more likely to need help with breathing. People who had nerve damage that affected the face, or who were unable to cough, stand, lift their elbows or lift their head, were also more likely to need help with breathing. In turn, people who needed help with breathing were also less likely to do well after treatment.

How reliable are the findings?

Reviews like these can be useful for looking at information from a lot of studies, and often the more studies that are included in a review, the more reliable the results tend to be. The researchers noted though that the majority of people who took part in the study were unable to walk and were already severely disabled at the beginning of the study. This could have influenced how well they did after taking treatment, and made the results less reliable.

What does this mean for me?

Guillain-Barré syndrome is a complex illness and it’s not easy for doctors to know what is likely to happen to individuals. It could be useful, if you have Guillain-Barré syndrome, to have some insight into what is likely to happen, and if you have treatment how likely it is to help your symptoms. Studies like these look at evidence from large groups of people and make conclusions based on averages, but they can’t tell what is likely to happen to you. This study has flagged up some potential things that might predict who is likely to do better or worse after treatment for Guillain-Barré syndrome. But the researchers themselves say we will need a lot more research, and further studies, before we can be sure if these things are definitely linked to improvements for people with Guillain-Barré syndrome.