

This questionnaire has been designed to gain information from people who have had Guillain Barré syndrome in the past or who still have GBS. We are trying to gain as much information as possible about what it has been like for you living with GBS and would very much value your comments and opinions. As you will be aware, GBS is a very rare condition and little is known about the psychological effects that having GBS has on individuals, so please give as much information as you can and do not hesitate to contact me if you need further information. Many thanks in advance for taking the time to complete this questionnaire.

1. Are you? Male Female
2. What is your age? Your date of birth? DDMMYY
3. Have you had any previous contact with mental health services (prior to having GBS)?
yes no
4. Do you have a history of misusing alcohol/prescription/non-prescription drugs (prior to having GBS)?
yes no
5. When did you contract GBS?
DDMMYY
6. Were you admitted to hospital?
yes no
7. Were you admitted to intensive care?
yes no
8. Did you
 Never lose the ability to walk?
 Lose the ability to walk but were not ventilated?
 Need to be on a ventilator?
9. If ventilated, for how long?

10. What treatment did you receive?

- IVIG
- Plasma exchange
- Both
- None
- Don't know

11. Were you sedated during your treatment?

- yes no

12. If yes, for how long?

13. Which category do you believe best fits with your degree of recovery?

- Fully recovered
- Good recovery with some residual problems
- Reasonable recovery
- Poor recovery but can walk unaided
- Walk only with sticks or crutches
- Remain wheelchair bound

14. Do you feel that you were given adequate information about GBS?

- yes no

Please give details of what information/support was helpful to you. Alternatively, if you feel you were not given enough information/support, what would have been helpful for you?

15. Were you able to communicate your needs to the staff/your family?

- yes no

16. Has GBS impacted upon areas of your life?

- yes no

17. If you have answered yes to the above question, please tick as many boxes below which you feel described your main concerns DURING THE FIRST 3 MONTHS AFTER YOU RECEIVED A DIGNOSIS

- | <i>Practical Concerns</i> | <i>Personal Concerns</i> | <i>Emotional Concerns</i> | <i>Physical Concerns</i> |
|---|--|--|--|
| <input type="checkbox"/> Family Issues | <input type="checkbox"/> Appearance | <input type="checkbox"/> Anger/Irritability | <input type="checkbox"/> Breathing |
| <input type="checkbox"/> Issues with health staff | <input type="checkbox"/> Self-care | <input type="checkbox"/> Nervousness/anxiety | <input type="checkbox"/> Eating/weight |
| <input type="checkbox"/> Finances/ bills | <input type="checkbox"/> Loss of independence | <input type="checkbox"/> Depression/ hopelessness | <input type="checkbox"/> Constipation/ diarrhoea |
| <input type="checkbox"/> Lack of information | <input type="checkbox"/> Loss of role | <input type="checkbox"/> Worry about GBS | <input type="checkbox"/> Fatigue/Exhaustion |
| <input type="checkbox"/> Problems with medication | <input type="checkbox"/> Sexual/ Intimacy issues | <input type="checkbox"/> Hallucinations/ odd experiences | <input type="checkbox"/> Sleep problems |
| | <input type="checkbox"/> Spiritual issues | <input type="checkbox"/> Memory/ concentration | <input type="checkbox"/> Nausea |
| | | <input type="checkbox"/> Self-esteem/ confidence | <input type="checkbox"/> Headaches |
| | | | <input type="checkbox"/> Pain |
| <input type="checkbox"/> Other | <input type="checkbox"/> Other | <input type="checkbox"/> Other | <input type="checkbox"/> Other |

18. Please tick as many boxes below which you feel described your main concerns DURING THE FIRST YEAR AFTER YOU RECEIVED A DIGNOSIS

- | <i>Practical Concerns</i> | <i>Personal Concerns</i> | <i>Emotional Concerns</i> | <i>Physical Concerns</i> |
|---|--|--|--|
| <input type="checkbox"/> Family Issues | <input type="checkbox"/> Appearance | <input type="checkbox"/> Anger/Irritability | <input type="checkbox"/> Breathing |
| <input type="checkbox"/> Issues with health staff | <input type="checkbox"/> Self-care | <input type="checkbox"/> Nervousness/anxiety | <input type="checkbox"/> Eating/weight |
| <input type="checkbox"/> Finances/ bills | <input type="checkbox"/> Loss of independence | <input type="checkbox"/> Depression/ hopelessness | <input type="checkbox"/> Constipation/ diarrhoea |
| <input type="checkbox"/> Lack of information | <input type="checkbox"/> Loss of role | <input type="checkbox"/> Worry about GBS | <input type="checkbox"/> Fatigue/Exhaustion |
| <input type="checkbox"/> Problems with medication | <input type="checkbox"/> Sexual/ Intimacy issues | <input type="checkbox"/> Hallucinations/ odd experiences | <input type="checkbox"/> Sleep problems |
| | <input type="checkbox"/> Spiritual issues | <input type="checkbox"/> Memory/ concentration | <input type="checkbox"/> Nausea |
| | | <input type="checkbox"/> Self-esteem/ confidence | <input type="checkbox"/> Headaches |
| | | | <input type="checkbox"/> Pain |
| <input type="checkbox"/> Other | <input type="checkbox"/> Other | <input type="checkbox"/> Other | <input type="checkbox"/> Other |

19. Were you able to return to work after having GBS?

yes no

If you answered no to the above question please answer questions 20/21

20. Would you like to be able to return to work?

yes no

21. What do you feel is the main reason that you cannot return to work?

If you would like any further information, need a larger font providing or there is anything you do not understand please contact Catherine Harrison: 104 Regent Road, University of Leicester, Clinical Psychology, Leicester. LE17LT (0116 2231639)

Many thanks for your time.