1) When were you diagnosed with epilepsy?

2) What type of seizure(s) do you have?/Do you have more than one seizure type?

**Generalised – loss of consciousness**

- **Tonic clonic** - Muscle stiffening (tonic stage) and fall to the ground, followed by jerking/convulsive movements (clonic stage). Can last several minutes (previously known as ‘grand-mal seizures’).
- **Tonic** - Muscle stiffening, fall to the ground.
- **Atonic** - Loss of muscle tone, fall to the ground. Recovery usually swift.
- **Myoclonic** - Muscle jerks. Loss of consciousness is usually so brief it is hardly noticeable.
- **Absence** - Often mistaken for day dreaming. Person goes into brief trance-like state (previously known as petit-mal seizures).

**Other – Please describe.**

**Focal - consciousness can be impaired or fully maintained**

Do you experience any of the following symptoms?

- De-ja vu.
- Change in emotions.
- Muscle weakness.
- Rapid eye-blinking.
- Seeing patterns/flashing lights or colours.
- Tingling/warm sensations. A feeling that limbs are different sizes.

**Other - Please describe.**
3) When was your last seizure?

4) How often do you have seizures?

5) Do you find your seizures are triggered by anything? e.g. tiredness/stress/flashing lights

6) When do most of your seizures occur?

   Morning.
   During the day.
   Evening.
   During the Night.
   They are variable (please state if they have any pattern).

7) What action would you like taken by members of staff and peers if you were to have a seizure? e.g. contact next of kin, call an ambulance, move objects away from you, let the seizure run its course

   N.B Please note, if a seizure lasts for more than 5 minutes, or for 2 minutes longer than is usual for that person, an ambulance should be called.

8) How long does it take you to recover after your seizures?
9) Do your seizures cause any side effects? If so what are they? e.g. headaches/tiredness

a. Do your seizures or these side effects impact on areas of your life? e.g. studying, going out, working

10) Are you currently taking antiepileptic medication?
   Yes [ ]  No [ ]

   a. If yes, do you find it causes any side effects? e.g. drowsiness/tiredness, difficulty with concentration, changes in mood/behaviour

   b. Do you find your medication and/or side effects impact on areas of your life? e.g. studying, going out, working

11) Are you receiving any other treatment for your seizures? e.g. VNS therapy/Ketogenic diet
   Yes [ ]  No [ ]

   If yes and happy to, please state the nature of the treatment

   a. If yes, do you find this treatment causes any side effects? e.g. drowsiness/tiredness, difficulty with concentration, changes in mood/behaviour

   b. Do you find your treatment or its side effects can impact on areas of your life? e.g. studying, going out, working
12) Have you previously received any support from school or college? Yes ☐ No ☐
   a. If yes, what support did you receive? e.g. extra time in exams, one to one support


13) Did you find this support useful? Yes ☐ No ☐
   a. Are you able to tell us why this was?


14) If you could, would you change anything about the support you received at school or college, and if so, what would it be?


15) Do you feel your epilepsy or its management impacts your education? Or that your education can affect your epilepsy? e.g. stress can mean more seizures, having absence seizures in class, finding it hard to concentrate


16) Do you already live in/are you planning on moving into university accommodation?


17) Do you currently have any safety or support measures in place at home? e.g. cooker guards, seizure alarms, taking showers rather than baths


18) Do you have any concerns about dealing with your epilepsy at university? If so what are these?


19) Is there anything you feel the university could do to help with these concerns?
Shared Information

Seizure types, how they present and what action should be taken.

Seizure frequency/What time of day they usually occur.

Effect of seizures and medication.

Seizure triggers.

Impact on education.

Current support in place.

Who this information will be shared with.

1) 2) 3) 4)

☐ Young Epilepsy would like to use the information in this questionnaire to shape our future resources and services. We aim to better support all young people living epilepsy and your experiences can help us to do this. If you are happy for this information to be shared with us and for us to contact you occasionally, please tick this box and provide a contact name and email address. All information will be treated confidentially, not shared with any third parties and only be used for the purpose stated.

Name: Email:
Address: Phone No:

Please return a copy of this questionnaire to National Services University Project, Young Epilepsy, St Piers Lane, Lingfield, Surrey RH7 6PW or email helpline@youngepilepsy.org.uk
Follow our tweets: twitter.com/youngepilepsy
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Download our free app: youngepilepsy.org.uk/app

If students want more information about epilepsy and higher education, we have a dedicated section on our website where they can find out more youngepilepsy.org.uk/students

Young Epilepsy Helpline
01342 831342 (Monday – Friday, 9am – 1pm)
helpline@youngepilepsy.org.uk
Text us: 07860 023 789

Better futures for young lives with epilepsy

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