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| **My Epilepsy Care Plan**  **NHS No :** | | | |  |
| **ABOUT ME** | | | | |
| 1.1 | **My Name** |  | | |
| 1.2 | **My date of birth** |  | | |
| 1.3 | **My Address** |  | | |
| 1.4 | **My Emergency Contacts** |  | | |
| **PROFESSIONALS INVOLVED IN MY CARE** | | | | |
| 2.1 | **My GP** |  | | |
| 2.2 | **My Epilepsy Nurse**  **(local team)** |  | | |
| 2.3 | **My Epilepsy Doctor (local team)** |  | | |
| 2.4 | **My Epilepsy VNS team**  **(tertiary team)** |  | | |
| 2.5 | **My School/Nursery** |  | | |
| **ABOUT MY EPILEPSY** | | | | |
| 3.1 | **My Diagnosis** | |  | |
| 3.2 | **My Regular Medications**  *Doses change with weight so please check* | |  | |
| 3.3 | **About my Vagus Nerve Stimulator**  **(VNS)** | | **Date of Implantation:**  **Device:** Sentiva 1000  **Generator Model: Serial number:**  **Lead Model: 303   Serial number:**  **Date of Activation:**  **My VNS is cared for at**: | |

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| **EMERGENCY SEIZURE PLAN AND MEDICATION** | | | | | |
| 3.3 | **My Emergency Medication**  *Instructions of when to administer below* | | |  | | --- | | Buccal Midazolam 1st Dose 2nd Dose |   **Prescriber:** Name Signature Date  ………………………… …………………………….. ………………. | | |
| 3.5 | Seizure type 1  **Generalised Tonic-Clonic Seizure (convulsive)** | | |  |  | | --- | --- | | **Known Triggers** |  | | **Description** |  | | **Duration/frequency** |  | | **Recovery** |  | | **Emergency Medication** |  | | **VNS Plan** | Swipe once at the onset of the seizure – the stimulation will begin for 1 minute  If the seizure continues for longer than 1 minute, then swipe a second time  If the seizure continues for longer than 2 minutes then swipe a 3rd time  Further swipes are unlikely to be helpful and you should proceed to emergency protocols and medications.  When the VNS is stimulating, it will lock out for 1 minute and swipes will be ineffective. It is therefore important that you time the seizure and administer 2nd and 3rd swipes after a period of 1 minute from the last swipe | | **Important info** |  | | | |
| 3.6 | Seizure type 2  Convulsive/non convulsive | | |  |  | | --- | --- | | **Known Triggers** |  | | **Description** |  | | **Duration/frequency** |  | | **Recovery** |  | | **Emergency Medication** |  | | **VNS Plan** | Swipe once at the onset of the seizure – the stimulation will begin for 1 minute  If the seizure continues for longer than 1 minute, then swipe a second time  If the seizure continues for longer than 2 minutes then swipe a 3rd time  Further swipes are unlikely to be helpful and you should proceed to emergency protocols and medications.  When the VNS is stimulating, it will lock out for 1 minute and swipes will be ineffective. It is therefore important that you time the seizure and administer 2nd and 3rd swipes after a period of 1 minute from the last swipe | | **Important info** |  | | | |
| 3.7 | Seizure Type 3  Convulsive/non convulsive | | |  |  | | --- | --- | | **Known Triggers** |  | | **Description** |  | | **Duration/frequency** |  | | **Recovery** |  | | **Emergency Medication** |  | | **VNS Plan** | Swipe once at the onset of the seizure – the stimulation will begin for 1 minute  If the seizure continues for longer than 1 minute, then swipe a second time  If the seizure continues for longer than 2 minutes then swipe a 3rd time  Further swipes are unlikely to be helpful and you should proceed to emergency protocols and medications.  When the VNS is stimulating, it will lock out for 1 minute and swipes will be ineffective. It is therefore important that you time the seizure and administer 2nd and 3rd swipes after a period of 1 minute from the last swipe | | **Important info** |  | | | |
| **CARE PLAN AGREED BY** | | | | | |
| Epilepsy Nurse  Name | | Sign:  Date: | | Epilepsy Consultant  Name | Sign:  Date: |
| Parent/Carer  Name | | Sign:  Date: | | Representative from school or nursery (if appropriate) | Sign:  Date: |
| **Care plans with emergency medication are routinely reviewed at 12 month intervals, unless there is a change to the emergency protocol (in which case the plan should be updated to reflect this). Please note that this is a guideline and care plans do not expire, so please do not refuse children to attend school or participate in any activity due to a care plan review date passing. Epilepsy teams ask that parents also take joint responsibility for getting reviews of plans in a timely manner. If you notice that this plan was reviewed more than 12 months ago then please ask the child’s parents to contact their epilepsy team to request a non-urgent review, and continue to use this plan until the review is undertaken.** | | | | | |

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| VAGUS NERVE STIMULATOR | |
| 3.8 | Vagus nerve stimulation - The Epilepsy Space  Vagal Nerve Stimulation has been used in the treatment of epilepsy since 1997. It is a surgical device that is implanted around the Vagus nerve in the neck, attached to a battery that is placed beneath the skin under the left collar bone. It sends tiny electrical impulses to the vagus nerve, which communicates between the body and the brain. It helps to reduce seizure frequency.  The device is set to stimulate the vagus nerve usually every 5 minutes. Some of the newer models are also set to activate an additional stimulation when the heart rate increases (which can happen before a seizure for some patients). An additional stimulation can also be activated externally using a special magnet when a patient feels a seizure coming on or is experiencing a seizure.  The potential advantages of this are:   * + Stop the seizure   + Shorten the seizure   + Decrease the severity of the seizure   + Improve the post-ictal recovery period following the seizure   The most common side effects of VNS therapy may include:   * + Temporary hoarseness / changes in voice tone   + Cough   + Tickling in the throat   + Shortness of breath   **How to use the magnets**  The magnets are thin black strips that are attached to a strap, which can be worn like a wristwatch (as above), or clipped to a belt like a pager.  In order to activate the device pass the magnet over the upper left chest area for about one second. You will not hear the device being activated.  How Does Vagus Nerve Stimulation Work?  The magnet should be kept at least 25cm away from credit cards, televisions, computers, computer discs, microwave ovens and other magnets. Do not drop the magnet. It can break if it falls on a hard floor.  At the onset of ANY seizure or during a seizure you can activate the device by swiping the magnet ONCE over the site of the VNS. You should only aim to use the magnet 2- 3 times but If the seizure continues follow the patient’s individual seizure care plan for emergency treatment. In order to stop the VNS device urgently, the magnet is held or taped over the site of the VNS device. |

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| **WHAT TO DO IF I HAVE A SEIZURE – FIRST AID** | | |
| 4.1 | If I have a convulsive seizure  See the source image | * Ensure that I am in a safe environment (e.g. not exposed to traffic) and remove dangerous objects from my space * Place me on my side if/when possible and support my head to prevent injury, but do not restrain me * Note the time the seizure began, time the duration * Monitor my breathing at all times * Do not put anything in my mouth * If safe to do so record a video of the event |
| 4.2 | If I have a non-convulsive seizure  Focal/Absence | * Do not try to stop the seizure * Stay with me throughout the seizure and call for help if needed * Lead me to a place of safety and privacy * Offer me verbal reassurance, repeat things that I may have missed * Note length of seizure and record |
| 4.3 | When to call 999 for an ambulance | * If you are concerned that I am not breathing properly * If you have had to give me emergency medication and my seizure has not stopped after 10 minutes * If I have dribbled the dose out, or there is a reason that the dose was abandoned * If I have injured myself * If you are concerned |
| 4.4 | What to do after a seizure | * Place me in the recovery position (on my side) if appropriate. * Stay with me and offer lots of reassurance. * Record the time and duration of the seizure (how long it lasted for). * If you are concerned I have not recovered fully call an ambulance. * If you are happy that I am fully recovered, inform my parents or keep a record of the seizure in my Seizure Diary depending on previous advice. |

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| **HOW TO ADMINISTER BUCCAL MIDAZOLAM (Epistatus)** | |
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| **FURTHER INFORMATION – SEIZURE SAFETY** | | |
| 6.1 | For healthcare professionals  Paramedics/hospitals | On arrival in hospital please treat status epilepticus as per APLS Guidelines <https://www.apls.org.au/algorithm-status-epilepticus>  Add Specific instructions here – such as resp depression with benzos, or bespoke plans for ambulance and A&E staff here |
| 6.2 | Safety advice for schools | Epilepsy increase the risk of accidents and injury, as during a seizure I might fall down, lose consciousness, or have muscle movements that I can’t control. Not everyone has the same level of risk, and seizure type and frequency are important factors. Activities involving Heights, Traffic, Water, Sources of heat or power increase the risk. It is important that all children (despite the diagnosis of epilepsy) are encouraged and enabled to participate in all activities, individual risk assessments in your areas should include the following questions   * How often does the child/young person have seizures – are they frequent? * What happens during a seizure – does the seizure cause the child to fall, jerk or wander? * Where the child/young person is – are they in a road, near water or other hazards? * What they are doing – are they climbing, running, cycling, cooking, or using scissors? * Who they are with – are they with someone trained in seizure safety / first aid?   For further information please visit:  [**https://www.epilepsy.org.uk/info/daily-life/safety**](https://www.epilepsy.org.uk/info/daily-life/safety)**.**  [**https://www.epilepsypace.org.uk**](https://www.epilepsypace.org.uk)  **https://www.epilepsy.org** |
| 6.3 | Safety Advice for seizures in water | As a general rule, children with epilepsy should be encouraged to take part in swimming. A designated person must be allocated to observe the child whilst in the water (at all times). If a seizure occurs in the water, then please follow this advice:  **Convulsive seizures**  From behind, tilt the child’s head so it is out of the water.  If possible, move the child to shallow water.  Shout for a lifeguard to help you get the child out of the water.  Once the child is out of the water, follow the above first aid advice for convulsive seizures.  **Non Convulsive seizures**  Protect the person from danger, for example by guiding them away from deep water or by holding their head above the water. When they recover, check if they need to get out of the water as they may feel confused and need to rest. |
| 6.4 | Training for Schools | Please be aware that the children and families act 2014 places a legal responsibility on schools to access training for children with epilepsy. It is not the epilepsy team’s responsibility to fulfil this obligation, and due to the large caseloads that we support in the hospital, it is not possible to train every school in basic epilepsy awareness, and you should approach your school nursing team if you need this. We recommend all school staff undertake the following free online training: [**https://learn.epilepsy.org.uk/courses/epilepsy-for-teachers/**](https://learn.epilepsy.org.uk/courses/epilepsy-for-teachers/) Please contact the epilepsy nurse for a discussion around the child’s individual care plan if the child is receiving rescue medication, but please note that this will only be offered as a virtual meeting once the above course has been completed and certificate sent by email. |
| 6.5 | Advice for parents | **Online Epilepsy Course for parents (free)**  <https://learn.epilepsy.org.uk/courses/your-child-and-epilepsy/>  **Seizure alarms** – we do not fund or endorse any particular brand of seizure alarm due to the lack of evidence around the reliability of monitors, and a simple baby monitor with a camera can be used. You can view the available alarms on the market here:  <https://www.epilepsy.org.uk/living/safety-equipment/alarms-and-monitors>  <https://www.youngepilepsy.org.uk/sites/default/files/dmdocuments/Night-safety-equip-126-2%20(1).pdf>  **SUDEP** – this is a rare complication of epilepsy. To read about this and learn how to manage risks  <https://sudep.org/>  **Further Reliable resources**  <https://www.epilepsy.org.uk/>  <https://www.youngepilepsy.org.uk/> |