

**Celebrating  
Outstanding Practice**



# Epilepsy Practice

Summary: This report is a deep dive into the safe care and treatment of epilepsy management in SJOG.

The report will highlight the experiences of those SJOG support, and also feedback from a number of professionals.



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**CHIEF OPERATING OFFICER/NOMINATED INDIVIDUAL**

**Summary of report:** This report is a 'deep dive' into epilepsy practice within SJOG services. We reviewed the most up to date literature on epilepsy, and considered best practice guidance on epilepsy management.

We also spoke with the people we support on their experiences of epilepsy, and asked if they felt safe and supported. We also asked how we could improve on the support we provide.

We spoke with professionals about SJOG's management of epilepsy, and asked them how we could improve.

Service Managers were invited to review epilepsy support plans, risk management plans, training and contingency planning for the management of epilepsy.

The following report provides the findings of this deep dive, including the learning and actions undertaken.

## Services Involved

The services that are represented all support people who have a diagnosis of epilepsy and also all registered with the Care Quality Commission:

Terry Yorath House, Leeds (Anthony Beech)  
The Minims, Hertfordshire (Migmar Yangchen)  
Sandown Road, Stockton on Tees (Jess Hazlewood)  
Dalby View, Middlesbrough (Richard Sellars)  
1 Bede's Close, Bradford (Tracy Duggan)



## Why are we reviewing Epilepsy Practice in SJOG?

Epilepsy is more common in people with a learning disability than in the general population.

About 1 in 3 people (32%) who have a mild to moderate learning disability also have epilepsy. The more severe the learning disability, the more likely that the person will also have epilepsy. Around 1 in 5 people (20%) with epilepsy also have a learning disability. In terms of the prevalence of epilepsy in people with autism, recent research suggests this is 12.1%.

**The population of people within SJOG that has epilepsy is currently 1.9%. All of these people either have a learning disability and/or autism.**

This deep dive is purely a 'safety check' into our practice. We **'think'** we support people well with their epilepsy, however we want to **'know'** that we do this well. Research is constantly informing practice, so we also want to ensure that our practice is meeting the highest possible standards.

## What are the aims and objectives of this deep dive?

1. We will listen to people who have epilepsy and understand their experiences of epilepsy, and their treatment;
2. We will speak with professionals and ask for their feedback on support and risk management plans;
3. We will evaluate all current epilepsy support and risk management plans to assure these are compliant with Health & Social Care Regulation;
4. We will evaluate all epilepsy support and risk management plans to ensure they are personalised to people's needs and wishes;
5. We will evaluate if information is presented in a clear way, and in accordance with the latest best practice guidance.
6. We will review our training to ensure this is robust.
7. We will learn and improve our practice in epilepsy management and identify actions to take forward.



## Listening and learning from people who have a diagnosis of epilepsy

We asked a range of questions to people who have epilepsy. All of the people we asked had capacity to consent and answer these questions.

### How involved are you in developing your epilepsy support plan?

People who had capacity informed us they are fully involved in the development and on-going monitoring of their epilepsy management plans. They were able to go into detail and describe their type of epilepsy and the medication they take, and also the support they receive.

Those that lack capacity shows an area of development need. Most plans appear to be either completed with the professional, or some not at all and completed by managers. When asked if family members or advocates were involved to offer additional support to the person, this was somewhat lacking.

### Are you encouraged and supported to review your epilepsy?

**S said:** "Yes my GP did a full medical review last year and always yearly if there is a change to any my medication. My GP will review and take into account my epilepsy when looking at all my medication and any changes".

**A said:** "Every year I have my annual check-up with GP he looks at everything".

**B said:** "My sister supports me for my epilepsy appointments".

This is however a stark difference to people with more severe learning disabilities, and a number of the people SJOG support are not provided with a formal annual review. We will correct this.

### Are your wishes and preferences respected?

**S said:** "Yes I suppose so, if I have a Grand Mal seizure my dignity and wishes would be to have a female staff member as my dignity is compromised as you can be incontinent and need changing".

**A said:** "Yes, people don't always know what my type of Jacksonian syndrome is and the staff should really look up what it consists of. Most of the staff team know but maybe not new staff but absolutely my wishes and preferences are respected".

**In people who lack capacity further improvements are required in capturing the evidence of decision making and best interests.**

### Do you feel safe in the actions taken by staff when you are experiencing seizure activity?

**K said:** "Yes I always feel safe. The staff look after me well when I have a seizure. They also sit with me afterwards so that I am reassured".

**Family:** "I am always informed when my son has a seizure. The staff are great like that, as they reassure me just as much as they reassure him".

### Is there anything that we could improve on, in the management of your epilepsy?

**Family:** "I would like to attend any training if that was possible? It would help me understand the signs of a seizure and how to help my son when I visit him".

## SJOG's Epilepsy Policy

SJOG first reviewed their Epilepsy Management Policy in 2019 following a full policy review. The policy has been reviewed on a further two occasions. The policy has been clinically reviewed by qualified nurses over this time.

There is evidence within the policy, that it has been written within the best practice guidance of the Epilepsy Society and NICE Guidance.

### Policy strengths

- Describes each type of seizure
- Triggers are provided for consideration
- Symptoms of seizures and the Do's and Don'ts of what safe support looks like
- Emergency advice is clearly explained and recorded
- Recording of seizures and a template is provided
- All training is refreshed after 3 years
- The policy was not due for a review until November 2023, however this deep dive ensured we review the policy proactively alongside the deep dive

### Policy weaknesses

- The policy did not include SUDEP—this has since been added with an explanation of the condition
- There were no 'good practice' guidelines on the writing of an epilepsy management and risk plan—this has since been corrected with the inclusion of a fact sheet to prompt colleagues writing plans
- Business continuity testing was not considered in the policy, as a way of testing competency. This meant services were reliant on a single training course. A new testing report has been established so that colleagues/managers can undertake randomised drills/tests of knowledge to ensure both practical skills and knowledge remain high
- Related policies did not consider the business continuity aspect of epilepsy, therefore this has been included

## Epilepsy Support Plans

- **Are they person centred?**

**Reflections:** Colleagues felt that plans were generally person centred, however could be improved upon to reflect this better. Decisions, in some cases are being made on people's behalf are recorded however need improvements in MCA & Best Interests to reflect the person centred needs of people.

- **Are plans clear?**

**Reflections:** Plans are not as clear as they could be. Often very lengthy and the salient points are therefore lost. Colleagues were recommended to follow the example of best practice in this report in terms of a structured template.

- **Do plans outline contingency for status situation?**

**Reflections:** No plans highlight the contingency planning for if and when status occurs. The question was asked if managers were confident that colleagues would be able to respond quickly, safely and effectively to a status situation—all confirmed they were not confident.

Discussed building this into a team meeting and also developing 'seizure drills' as a business continuity test.

- **Are they reflective of best practice?**

**Reflections:** Some epilepsy management plans do evidence best practice guidance, however this is not a common practice across all services. Provided feedback from professionals however find confidence in reading this in care planning.

Colleagues were advised to also apply for membership of the British Epilepsy Society or similar.

- **Do plans reflect the learning from residents?**

**Reflections:** This is not a common practice across the services, and should be. Colleagues advised that following every seizure, the person's epilepsy management plan should be reviewed. This should be recorded stating this.

- **Are people's rights and choices included in plans?**

**Reflections:** This is not as robust as it could be. Where people lack capacity, their families and professionals should be involved. This should be documented on the epilepsy management plan. It was advised that family members should be aware of the safe care and treatment provided with epilepsy support.

- **Did the plans demonstrate joint working?**

**Reflections:** Not all plans are developed in conjunction with other professionals. Those that are, appeared more robust and tended to be better structured. All colleagues were advised to ensure that professional involvement in epilepsy is assured during an annual review and for this to be recorded.

- **Assistive technology?**

**Reflections:** Technology is being used for a number of services. This is not documented in some care plans. Colleagues also advised to ensure this cross references with the person's DOL Authorisation, and where this is not the case a Best Interests has been completed.

## Epilepsy Reviews

- **Are reviews happening?**

**Reflection:** The majority of services stated that epilepsy reviews are not happening. Advice was provided that colleagues should actively seek reviews and request this even when epilepsy is well managed.

- **How do we capture epilepsy reviews?**

**Reflection:** As reviews are not occurring, these are not being documented. Advice provided requested that any reviews should be recorded on the Health Action Plan and then checked against the epilepsy management plan.

- **Had plans been reviewed within last 6 months?**

**Reflection:** All epilepsy management plans had been reviewed by managers within the last six months. The question of clinical competency was discussed , and whether these reviews were robust enough. All agreed that reviews should be annually requested with epilepsy specialists.

## Epilepsy Emergency Contingency Planning

- **Are we prepared?**

**Reflection:** Having undertaken this review, all colleagues felt that further work was needed to be better prepared. This starts with reviewing all epilepsy management plans against the best practice guidance in this report.

- **Are plans clear on what to do if the plan doesn't work?**

**Reflection:** A number of plans are clear and address the support required, whilst others lacked the detail and clarity. Advice provided on the structure of the epilepsy management plan within this report.

- **Seizure Drills?**

**Reflection:** Seizure drills have not been considered by colleagues, however once best practice examples were provided, everyone could see the value of this. It was agreed that to improve this area, operations would develop a Continuity Drill Sheet to capture evidence of emergency interventions and testing.

## Example of a good Epilepsy Support Plan

The following list of considerations for an epilepsy plan has been taken from good practice examples:

### Seizure History

- When was the person diagnosed?
- Write 'not known' if this is applicable

### Medication

- What medication is the person prescribed?
- Consider: Grapefruit juice and pomegranate juice do not trigger seizures, but they can make the side effects of some epilepsy medications more likely, including **carbamazepine, diazepam, and midazolam**.
- Is the person prescribed 'Emergency Rescue Medication'?

### Seizure Triggers

A trigger is a situation or event that can make a seizure more likely to occur :

- Not everyone will have known triggers however examples of common triggers include drinking too much alcohol, being hot or not well, lack of sleep etc.
- If not known write 'not known' if this is applicable.

### Behaviours

Some people get a 'sense' that they are leading up to seizure activity. For other people, their behaviour or mood may change. Many people have no such indication.

- A change in behaviour may occur for hours, days or weeks prior to a seizure •
- Examples of changed behaviour may include feeling sad, irritability or poor appetite
- Write 'not known' if this is applicable

### Seizures

- Determine all of the types of seizure the person has—if this is not known, as a medical professional.
- Describe how these seizures are presented—this should be BEFORE, DURING & AFTER.
- Do seizure occur in the night? What support/monitoring is provided? Is there a need for a low bed, crash mat etc?
- What is the typical duration of the seizures?
- Does the person require emergency medication? Include how this is administered.
- When would an ambulance be called?



## Support during a seizure

- Provide step by step instructions on how to support the person (including their wishes).
- Include dignity and privacy.

## Post seizure support

- As recovery from seizures varies greatly, state clearly what needs to be done to assist the person.
- State how long they should be supervised after a seizure.
- Describe how the support person would know when the person has regained their usual awareness and how long this typically takes.

## Risks/Safety Alerts

- Identify risks that the person may face, for example bathing, swimming, use of a helmet, mobility or eating after a seizure .
- After identifying the risk, state what the support person needs to do to reduce the likelihood of the danger .
- How is information to be recorded e.g. if the person has had a seizure during the night (or day) - e.g. what are the monitoring conditions?
- When would an appointment be required with the GP or Epilepsy Nurse?
- Is the person high risk of Sudden Death due to epilepsy (SUDEP) If so, this must be recorded - Important note: If SUDEP occurs a person's records are even more important as these may be needed in a coroner investigation or even inquest.
- ALWAYS CONSIDER BEST INTERESTS IF THE PERSON HAS BEEN ASSESSED AS LACKING CAPACITY - e.g. any monitoring devices, helmets etc.

## Useful Fact Sheets

**Epilepsy & Sport:** [Exercise and sport May 2022.indd \(epilepsysociety.org.uk\)](#)

**Diet & Nutrition:** [DietandNutritionFebruary2023.indd \(epilepsysociety.org.uk\)](#)

**Learning Disability:** [LearningdisabilityJan2023.indd \(epilepsysociety.org.uk\)](#)

**Photosensitive Epilepsy:** [Photosensitive epilepsy 2019.indd \(epilepsysociety.org.uk\)](#)

**Recovery Position:** [Recovery position August 2021.indd \(epilepsysociety.org.uk\)](#)

**Travel & Holidays:** [Travel and holidays May 2022.indd \(epilepsysociety.org.uk\)](#)

**Sleep:** [Sleep June2019.indd \(epilepsysociety.org.uk\)](#)

**Epilepsy & Mood:** [Links between epilepsy and mood Oct 22.indd \(epilepsysociety.org.uk\)](#)

**Exercise:** [Exercise and sport May 2022.indd \(epilepsysociety.org.uk\)](#)

**Seizure Observation & Recording Tips:** [72TSO\\_TipsSeizureObserRec\\_05-2019.pdf \(epilepsy.com\)](#)

## Epilepsy Management Training & Competency

The following analysis highlights the level of training & competency completed across services where we know there are people with epilepsy support needs.

This includes a Level 2 Certificate in Epilepsy Awareness and competency test, and Rescue Medication undertaken by external professionals.

Name of Service	Percentage of Epilepsy Management Training	Percentage of Rescue Medication Training
Sandown Road *	79%	100%
The Old Vicarage	100%	N/A
Dalby View	100%	N/A
Lindisfarne Court	97%	N/A
The Minims	88%	N/A
Terry Yorath House	100%	N/A
1 Bede's Close	93%	N/A
Rockcliffe Court	100%	N/A
Balmaclennan	100%	N/A
<b>AVERAGE % (KPI 95%)</b>	<b>95.2%</b>	<b>100%</b>

\* Sandown Road have a large number of new starters. KPI is low however all colleagues are enrolled on Epilepsy Management and rescue medication is fully completed to reduce risk.

GREEN: Indicates meeting SJOG KPI of 95% or over.

### Do we keep testing our business continuity on epilepsy management?

It is clear from reflections and discussions that once an epilepsy management plan is written, and colleagues have received initial training, that no further testing is completed. This is not uncommon across the industry, however to ensure competency and knowledge is kept up to date, this deep dive has exposed this risk.

Discussions took place on how these drills could be undertaken, and to also include time sensitivity due to the nature of epilepsy and the 5 minute procedure. We need to be able to test out colleagues responses, how they communicate in times of emergency (and possibly stress) etc.

We agreed we would develop a 'Drill Form' which can be used for epilepsy, and any other business continuity drill.

## Professional Feedback

We asked a range of professionals to provide us with feedback on how SJOG services' provided support to people with epilepsy. The following provides a summary of comments received:

### 1. Do SJOG demonstrate that they work closely with external professionals to ensure safe care and treatment for people who have a diagnosis of epilepsy?

**Epilepsy Nurse:** "Yes, we have regular contact regarding the people with epilepsy that are supported by this service, MDT discussions are always shared and considered in order for the best plan of care for each individual to be agreed."

**Epilepsy Nurse:** "I am pleased with the level of support X receives. The staff appear to know her well"

**GP:** "Staff often visit the surgery when they have a concern, rather than waiting until it is a significant health problem".

### 2. Do SJOG follow the latest guidance and best practice in their epilepsy management practice?

**Epilepsy Nurse:** "Yes, we share best practice guidelines and refer to them in any clinical discussion, Tracy and other members of the team always appear knowledgeable."

**Epilepsy Nurse:** "Yes they do, but it would be nice to see this is recorded in the epilepsy plan".

### 3. As a professional do you consider SJOG are proactive in their risk management of epilepsy?

**Epilepsy Nurse:** "Absolutely, care plans are in place and aim to minimize risks whilst acknowledging the individuals rights and freedom of choice."

**GP:** "The staff do the best to make sure patients health needs are responded too. I have never had a concern about this".

### 4. Are epilepsy management plans written clearly and demonstrate a good understanding of how to provide support to a person?

**Epilepsy Nurse:** "Yes"

**Epilepsy Nurse:** "I often advise and help to construct the epilepsy plan, mainly because I often see across all of my visits, plans that are not clear. I would like to see more best practice guidance recorded in the plans, but that is just my preference".

### 5. Are there ways you consider SJOG could improve on? If so, what are these?

**Epilepsy Nurse:** "I have always felt very confident in the care provided, seizure diaries appear to be kept up to date, medication is stored and managed appropriately and there is good engagement with health professionals."

**ICB Commissioning Team:** "We do like to see epilepsy plans related to the latest best practice, such as NICE Guidance. It gives us reassurance that the service (and the manager) is ensuring best practice in care planning."

## Actions to be Completed

1. Information fact sheet with research and good practice guidance. To be shared out to the wider organisation via Outstanding Managers Workplace. **Completed**
2. All epilepsy management plans and risk assessments for all 30 people to be reviewed and capture the good practice guidance set out in this document.
3. Business continuity testing: Managers required to drill down on all individual's epilepsy plans in their next team meeting. This should be a periodic review throughout the year.
4. We will develop a business continuity 'drill sheet' in order to capture evidence of emergency intervention testing. **Completed**
5. The Epilepsy Management Policy will be reviewed in light of the deep dive findings. **Completed**
6. To request epilepsy reviews for all individuals who have not received an annual check-up. To request these annually thereafter.
7. Services that support people with epilepsy, to consider becoming a member of the British Epilepsy Society.
8. Post deep dive review in September will be undertaken by the Chief Operating Officer to review all 30 epilepsy management care plans to ensure they meet the standards outlined in this deep dive.

**NOTE: The post deep diver review for all actions will take place on the 18th September by the Chief Operating Officer/Nominated Individual.**

## References

**Leestma** JE, Annegers JF, Brodie MA, *et al.* (1997) Sudden unexplained death in epilepsy: observations from a large clinical development programme. *Epilepsia* 38:47–55, NOTES. Reviews the subject and identifies overall risk and factors associated with greater risk of SUDEP

**Rani** A. Sarkis, Abbott Gifford, Zeina Chemali. (2023) Epilepsy and Behaviour. *Journal of Science Direct*. V144.

**Smith** D, Chadwick D. The Management of Epilepsy. *Journal of Neurosurgery & Psychiatry* 2001, 70:ii15-ii21.

## **Websites:**

[Autism and Epilepsy: Laying out the evidence | Epilepsy Research UK](#)

[Epilepsy Society | Transforming lives through advocacy, research and care](#)

[Epilepsy | Treatment summaries | BNF | NICE](#)

[Management | Epilepsy | CKS | NICE](#)

[rightcare-epilepsy-toolkit-v2.pdf \(england.nhs.uk\)](#)

## **Notes for discussion with colleagues: (Manager Only)**