APPENDIX the tools

purple light for epilepsy

how good are your epilepsy services for people with learning disabilities?

a service improvement toolkit

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SECTION ONE

SECTION TWO

SECTION THREE

purple light for epilepsy

how good are your epilepsy services for people with learning disabilities?

a service improvement toolkit

The ID Epilepsy service delivery and improvement self-assessment toolkit

Introduction

The toolkit is a proposal created by the amalgamation of the National Service Framework for people with chronic conditions and the Green light toolkit for mental health and ID

This self-assessment checklist is the core of the **purple light** toolkit. It is based on the self-assessment framework that mental health local implementation teams have been completing to assess their progress in implementing the National Service Framework (NSF) England for people with ID and the NSF for chronic conditions outcomes. Because the NSF applies to all adults of working age it should be expected that the provisions within it are available to people with Epilepsy problems who also have ID. This self-assessment framework aims to help local partnerships identify how well the service design for epilepsy for people with ID is being implemented in relation to providing care to people with epilepsy and ID

The checklist uses a scoring system based on traffic lights. All you have to do for your local area is decide whether it's a red, amber or green light that best matches the local situation.

Using the checklist

The checklist should help you to establish what's in place and working well for people with ID as a first step towards service improvement and development. You may decide that you need to gather more information before you can 'rate' some of the sections in the checklist – so that ratings are 'evidence based'.

Or, you may feel that you need to do more to establish your local partnership before embarking on the full self-assessment checklist. The first heading in the checklist focuses on local partnership arrangements between Epilepsy, ID, and primary care services including service users (people with ID who have Epilepsy problems), carers, and their representatives. If your local area rates a red light on partnership arrangements then it may be necessary to stop and build them up before progressing too far with the checklist. If one service fills out the checklist on its own it is unlikely to promote a sense of *shared* ownership and commitment to improving things for people with ID who have Epilepsy problems.

You may have many protocols and systems in place, but it is important to consider how things are actually working *in practice*. The checklist gives you space to comment on the actual implementation and impact of protocols, systems and services in your area.

Guidance for completion of the checklist

1. The framework should be completed by (at least) Epilepsy and ID services **as a partnership**, and ideally be based on a process that involves key stakeholder services, users and carers.
2. Remember, each statement should be considered as it relates to **services and support for people with Epilepsy problems who have an ID.**
3. The checklist uses descriptive statements. Circle **‘green’**, **‘amber’** or **‘red’** as appropriate for the statement that most nearly matches the situation in your locality. Some questions in the checklist also ask for the elements to be specified which contribute to your response. There is provision for this on the rating sheets.
4. Only circle ‘green’ if the situation is constantly positive across the whole of your local area. If it isn’t, circle amber or red – reflect the **poorest** level of progress across the locality.
5. Complete the checklist as openly and honestly as possible. Most localities will probably see the whole range of red, amber and green ratings. At this stage there are likely to be more red and amber ratings than green. The aim is to see a different distribution, more green and amber, in 2 or 3 years’ time.

Reporting on progress

At the end of this Section there is a summary and action-planning sheet, Measuring Success, (page 17) based on the checklist headings. It is designed to make it easy to present findings and conclusions to the Epilepsy Local Implementation Team and the ID Partnership Board, and to feed back to other key stakeholders.

Seeing change

Using the self-assessment checklist at regular intervals will help you to track developments, celebrate achievements and keep moving forward towards even better services and support for people with ID who experience epilepsy problems.

LOCALITY: **DATE:**

Local Partnerships

1	**Between Epilepsy and ID Services**
RED	There is no agreement between Epilepsy and ID services about commissioning and provision roles, frequent disputes between the two services and no plans for integrated service development.
AMBER	There is a degree of agreement between Epilepsy and ID services about commissioning and provision roles and responsibilities, but also some disputes.
GREEN	There is clear agreement between Epilepsy and ID services about commissioning and provision roles and responsibilities

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

2	**With Primary Care Services**
RED	There is no agreement between Epilepsy, ID and primary care services about the role and responsibilities of primary care staff, and referral routes for specialist support.
AMBER	There is a **degree** of agreement.
GREEN	There is **clear** agreement between Epilepsy, ID and primary care services about the role and responsibilities of primary care staff, and referral routes for specialist support.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

3	**With People with ID**
RED	People with ID have had **no involvement** in deciding on or agreeing the local service/support configuration and plans related to Epilepsy support or if historically set up to provide feedback and expectation.
AMBER	People with ID have had **some involvement in agreeing** the local service/support configuration and plans related to Epilepsy support or if historically set up to provide feedback and expectation.
GREEN	People with ID have **contributed to and agreed** the local service/support configuration and plans related to Epilepsy support or if historically set up to provide feedback and expectation.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

Local Partnerships

4	**With Carers of People with ID**
RED	Carers of people with ID have had **no involvement** in deciding on or agreeing the local service/support configuration and plans or if historically set up to provide feedback and expectation.
AMBER	Carers of people with ID have had **some involvement in agreeing** on or agreeing the local service/support configuration and plans or if historically set up to provide feedback and expectation.
GREEN	Carers of people with ID have **contributed to and agreed** the local service/support configuration and plans or if historically set up to provide feedback and expectation.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

Local Planning

5	**Commissioning - Planning**
RED	Commissioning of services/support for people with ID experiencing Epilepsy problems is **completely separate** from the commissioning of Epilepsy services and is **not linked into the Epilepsy Local Development Plan** (the comprehensive commissioning plan for Epilepsy services).
AMBER	There is a joint commissioning structure in place for Epilepsy services generally but **some commissioning** of services/support for people with ID experiencing Epilepsy problems **is separate** from it and not linked into the Epilepsy LDP (the comprehensive commissioning plan for Epilepsy services).
GREEN	There is a joint commissioning structure in place for Epilepsy services generally and services/support for people with ID experiencing Epilepsy problems are commissioned **through** that structure as **an integrated part of the Epilepsy LDP** (the comprehensive commissioning plan for Epilepsy services

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

6	**Commissioning – Health Act Flexibilities**
RED	There is **no pooling** of funds from health (PCT), LA, Epilepsy and ID services for the commissioning of services/support to meet the needs of people with ID experiencing Epilepsy problems.
AMBER	There is **some pooling** of funds from health (PCT), LA, Epilepsy and ID services for the commissioning of services/support to meet the needs of people with ID experiencing Epilepsy problems.
GREEN	There is **a pooled budget** with funds from health (PCT), LA, Epilepsy and ID services for the commissioning of services/support to meet the needs of people with ID experiencing Epilepsy problems.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

Access to Services

7 Agreed criteria and boundaries between services

Looking at the box below:

RED	**One or none** of the features apply.
AMBER	**Two** of the features apply.
GREEN	**All** of the features apply.

There are clear criteria for access to services by people with ID, agreed by commissioners, ID services & generic Epilepsy services

Entry criteria for generic Epilepsy services and specialist ID services overlap so that nobody is excluded by both services

Entry criteria for generic Epilepsy services for people with ID are based on Epilepsy needs, functional level and vulnerability

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

8 Transition Protocols

Looking at the box below:

RED	The arrangements for **both** of the following are **inadequate or ineffective** for people with ID who have Epilepsy problems.
AMBER	The arrangements for **only one** of the following are **adequate and effective** for people with ID who have Epilepsy problems.
GREEN	The arrangements for **both** of the following are **adequate and effective** for people with ID who have Epilepsy problems

- Transition of care between child and adolescent services and adult ID and Epilepsy services
- Transition between adult ID and Epilepsy services and services for general population for Epilepsy

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

Joint Working

9	**Roles, Responsibilities and Cross-Service Support**
	Looking at the box below:
RED	**One or none** of the features apply.
AMBER	**Two** of the features apply.
GREEN	**All** of the features apply.

Protocols for transfer or shared care between LD and generic Epilepsy services exist and clearly specify consultant responsibility

Protocols for transfer or shared care between LD and Epilepsy services exist and clearly specify the roles and responsibilities of in-patient and community teams in both Epilepsy and ID services

Where a person with an ID is having services from both Epilepsy and ID services there is joint care planning at an individual level

Where a person with an ID is having services from both Epilepsy and ID services the written care plan specifies what support each service can expect from the other.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

Key Services

10	**Carer's Services**
RED	There are no development plans or plans are insufficient to meet the respite and support needs of carers of people with Epilepsy problems who have ID.
AMBER	There are plans being implemented to provide a sufficient range and level of services to ensure that carers of people with Epilepsy problems who have an ID can get breaks and support to meet their needs.
GREEN	There is already a sufficient range and level of services to ensure that carers of people with Epilepsy problems who have an ID can get breaks and support to meet their needs.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

11 Black and Minority Ethnic People's Services

RED No data is being collected about people with ID from ethnic minorities who have Epilepsy related culturally sensitive problems and nothing is being reported to the LIT and Partnership Board. It is not part of service governance.

AMBER Data is collected about people with ID from ethnic minorities who have Epilepsy related culturally sensitive problems and reported to the LIT and Partnership Board **but** there is no link to service planning or service governance.

GREEN Data is ***collected*** about people with ID from ethnic minorities who have Epilepsy related culturally sensitive problems ***and reported*** to the LIT and Partnership Board. This is linked to service planning and monitored through service governance.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

12 Primary-secondary interface

Looking at the box below, how many of the listed features do you have in place locally?

RED **Up to two** are in place (please specify)

AMBER **Three** are in place (please specify)

GREEN **All four** are in place (please specify)

- There are primary care registers which identify people with an ID and Epilepsy
- There are Epilepsy/ID/primary care referral agreements (protocols), reviewed systematically to ensure they are effective
- There are protocols on exchange of information across Epilepsy, ID and primary care services
- There are systems and protocols for delivery of specialised support services to people with Epilepsy problems who have an ID on the primary care site (out- posted clinics, liaison workers, etc).

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

13

Acute Hospital Services

Looking at the box below, how many of the listed features do you have in place locally?

RED	**Less than 3** of these are in place (please specify)
AMBER	**3 to 5** of these are in place (please specify)
GREEN	**6** of these are in place (please specify)

- An agreement between Epilepsy and ID services about provision of specialised support for people with ID admitted to local general hospitals
- Local general hospital provision with staff who have significant Epilepsy training **and** knowledge/skills in supporting people with ID
- Sufficient local provision of the above to meet needs
- Advocacy support for people with ID so they can participate fully in staff/user forums on wards
- Named clinical and professional leads from **both** Epilepsy and ID services linked to hospital responsible for ensuring regular multi-disciplinary input
- Named consultant leads from **both** Epilepsy and ID services for each setting

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

14 Care Pathways (CP) – Shared Systems and Protocols

One or both services **do not use a common CP and/or** -

RED	There is no agreement between ID and Epilepsy services about roles, responsibilities and where people "fit" in relation to CP.
AMBER	Both Epilepsy and ID services in the local area operate CP but use different systems **and/or** Progress has been made towards an agreement between ID and Epilepsy services about roles, responsibilities and where people "fit" in relation to CP but it is **not yet finalised**.
GREEN	There is a **uniform system** for a CP ACROSS Epilepsy and ID services **and** There is a **clear agreement** between ID and Epilepsy services about roles and responsibilities in relation to CP including where people with Epilepsy problems who have an ID "fit" with a CP and how it will apply to them

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

15 CP- Sharing information and accessing Care Pathway Plans

Looking at the box below:

RED	**None** of the features apply.
AMBER	**One or two** of the features apply.
GREEN	**All** of the features apply.

CP recording systems allow the identification of people with an ID and such information is routinely recorded.

There is an agreed information sharing protocol between ID, Epilepsy, primary care services and other relevant local agencies.

Care plans for people with ID known to have Epilepsy problems can be accessed 24 hours a day by staff providing direct care to him/her from across services.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

Care Planning

16 CP- Person-Centred and whole life

Looking at the box below, how does your local CP system match up to the statements?

RED	Locally we **cannot say yes** to any of the statements.
AMBER	Locally we **can say yes to one or two** of the statements (please specify).
GREEN	Locally we **can say yes to all** of the statements.

The local CP system **is** person-centred in the way it operates and people with Epilepsy problems who have an ID are empowered by the process

The local enhanced CP system **does** include assessment and action planning for all of the following: Employment or other occupation; housing; welfare benefits; crisis plans, including 24-hour access arrangements. This information is always recorded and there are sufficient support services available to meet people's assessed needs in these areas.

There is a clear process for integrating someone's person-centred plan into their CP.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

Diversity of Provision

17 User led initiatives and services

RED	There are no initiatives or services in the area being led by people with ID who have Epilepsy problems (with appropriate support)
AMBER	Work is actively taking place to establish or increase the number of initiatives and services in the area being led by people with ID who have Epilepsy problems in the local area (with appropriate support)
GREEN	There are initiatives and services being led by people with Epilepsy problems who have an ID (with appropriate support) and there are enough to give an adequate mix with the overall service provider map.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

Diversity of Provision

18	**Voluntary Sector Services**
RED	There are no local Epilepsy voluntary sector services that offer support to people with Epilepsy problems who have an ID.
AMBER	There are local Epilepsy voluntary sector services that offer support to people with Epilepsy problems who have an ID but they struggle to appropriately respond to people's needs and/or their funding is not in place.
GREEN	There are local Epilepsy voluntary sector services that offer support to people with Epilepsy problems who have an ID. They are able to appropriately respond to people's needs and arrangements are in place to ensure continuity of funding.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

Underpinning Programmes

19	**Recruitment and Retention**
RED	There are **significant** problems with the recruitment and retention of staff and clinicians with knowledge/skills in both Epilepsy and ID.
AMBER	There are **some** problems with the recruitment and retention of staff and clinicians with knowledge/skills in both Epilepsy and ID.
GREEN	There are **no** significant problems with the recruitment and retention of staff and clinicians with knowledge/skills in both Epilepsy and ID.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

20	**Workforce Planning** (in local Epilepsy service delivery)
RED	An agreed cross-agency workforce strategy and related action planning are not in place and not yet in development.
AMBER	**Either** there is an agreed workforce strategy and related action planning across agencies but not covering all settings. **Or** A cross agency workforce strategy and action planning are being developed but are not yet finalised and agreed.
GREEN	There is agreed cross-agency workforce planning to ensure that staff knowledgeable and competent in Epilepsy and ID are available to support people in **any** setting. **And** It is integrated into the main Epilepsy and ID workforce planning.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

Underpinning Programmes

21	**Integrated HER**
RED	An Epilepsy electronic record spanning health and social care is not in place and/or there are no plans to identify/include people with Epilepsy problems who have an ID on it.
AMBER	Work is underway to ensure that people with Epilepsy problems who have an ID are identified and included on the Epilepsy electronic record spanning health and social care.
GREEN	People with Epilepsy problems who have an ID are identified and included on the Epilepsy electronic record spanning health and social care.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

22	**Local Directory**
RED	There is no comprehensive directory of local Epilepsy services or the one that exists does not include or identify services that work with people with Epilepsy problems who have an ID.
AMBER	There is work underway to include and specifically identify services that work with people with Epilepsy problems who have an ID in the local comprehensive directory of Epilepsy services.
GREEN	The comprehensive directory of local Epilepsy services includes and specifically identifies services that work with people with Epilepsy problems who have an ID

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

Other Priorities

23	**Epilepsy Promotion**
RED	There **is not** an Epilepsy promotion strategy that adequately addresses the requirements of people with an ID.
AMBER	There **is** an Epilepsy promotion strategy that adequately addresses the requirements of people with an ID and work is underway to integrate it into practice.
GREEN	An Epilepsy promotion strategy is being implemented that includes and adequately addresses the requirements of people with an ID.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

24	**Specialist Services**
	Looking at the box below, how many services do people with Epilepsy problems who have an ID have access to?
RED	**Only one or none** at a level sufficient for local needs (please specify).
AMBER	**Two or three** at a sufficient level for local needs (please specify).
GREEN	**Four of five** at a level sufficient for local needs (please specify).

- Services for people with sensory impairment and epilepsy
- Dietician
- Complex needs – PMLD
- Speech & Language Specialists
- Occupational Therapists
- Psychologists

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

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Measuring Success

Summary

DATE OF PLAN:	**DATE FOR PROGRESS REVIEW:**

What we are doing well on (our ‘green light’ areas)

What we are on track with, but there’s still more to do (our ‘amber light’ areas)

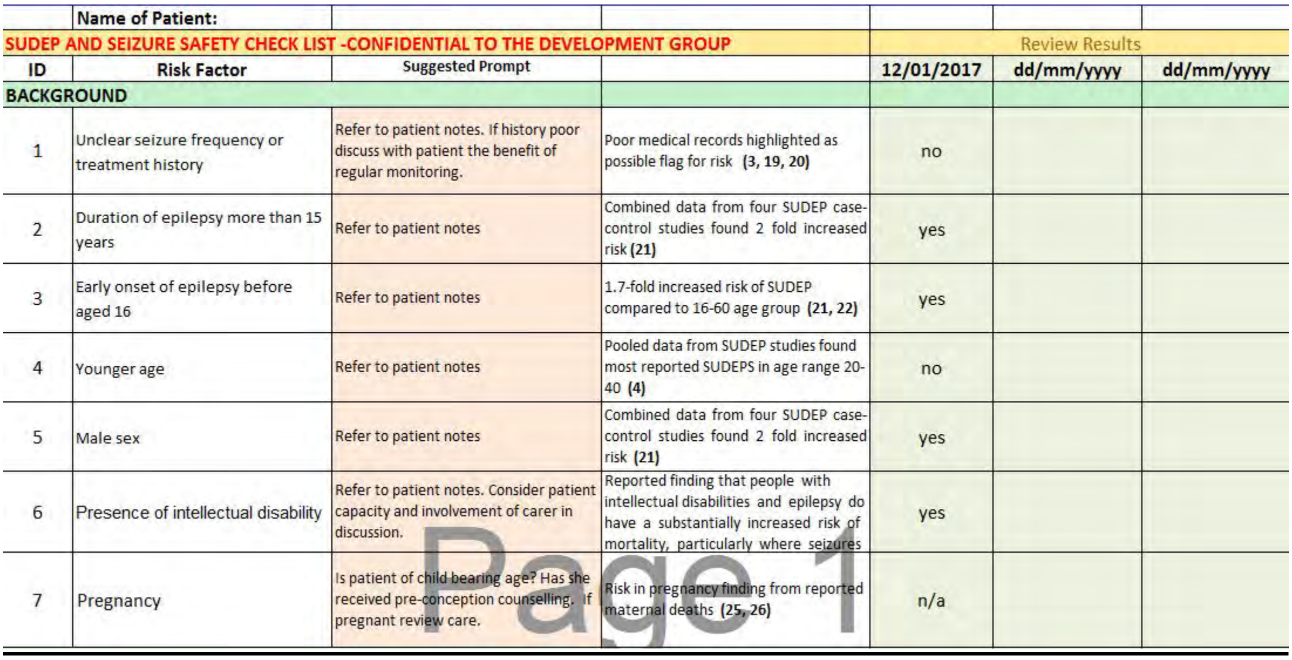
What we are not doing well on (our ‘red light’ areas)

Our 5 development priorities -	**and the reasons why**
1.	
2.	
3.	
4.	
5.	

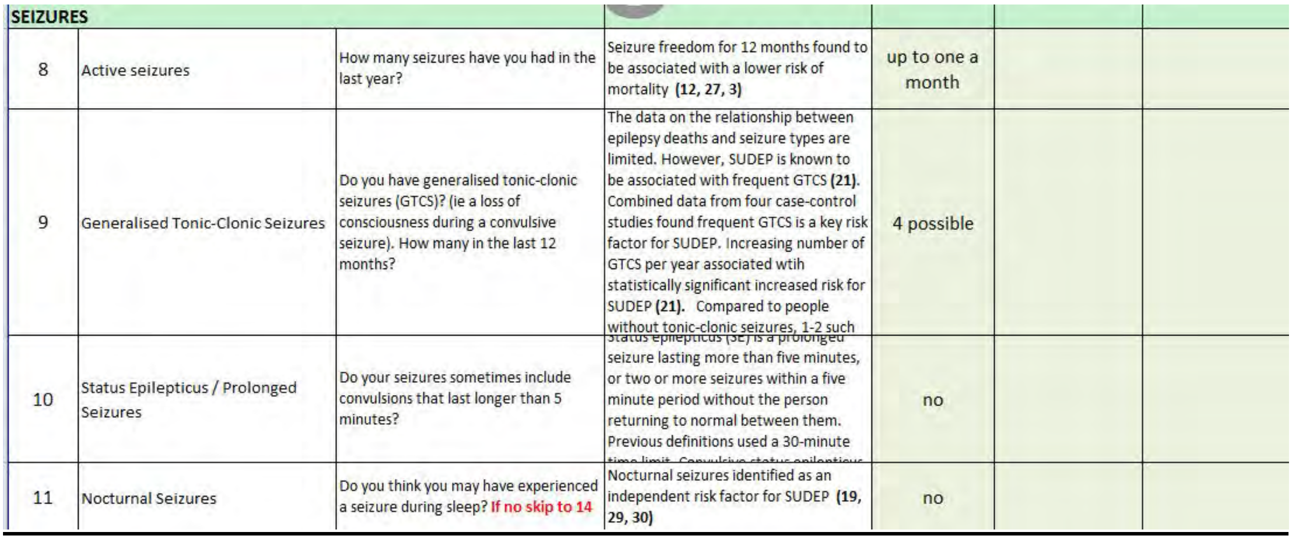
THE PRIORITY	WHAT WE PLAN TO DO	WHO IS THE LEAD	WHAT SUCCESS WILL LOOK LIKE	WHEN WE AIM TO HAVE ACHIEVED IT
Priority 1				
Priority 2				
Priority 3				
Priority 4				
Priority 5				

SUDEP SAFETY CHECKLIST

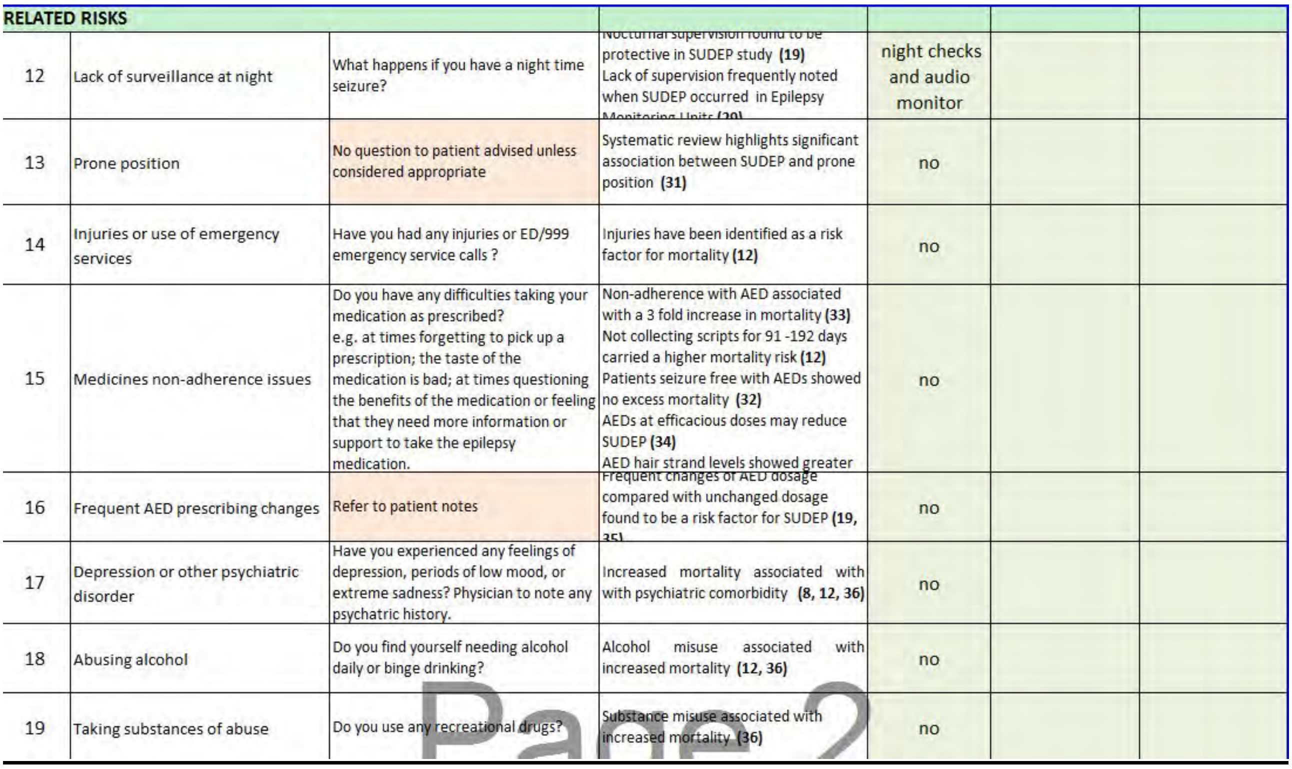
The below is a screenshot of the SUDEP Safety Checklist for reference only. The full document can be accessed via www.sudep.org/checklist



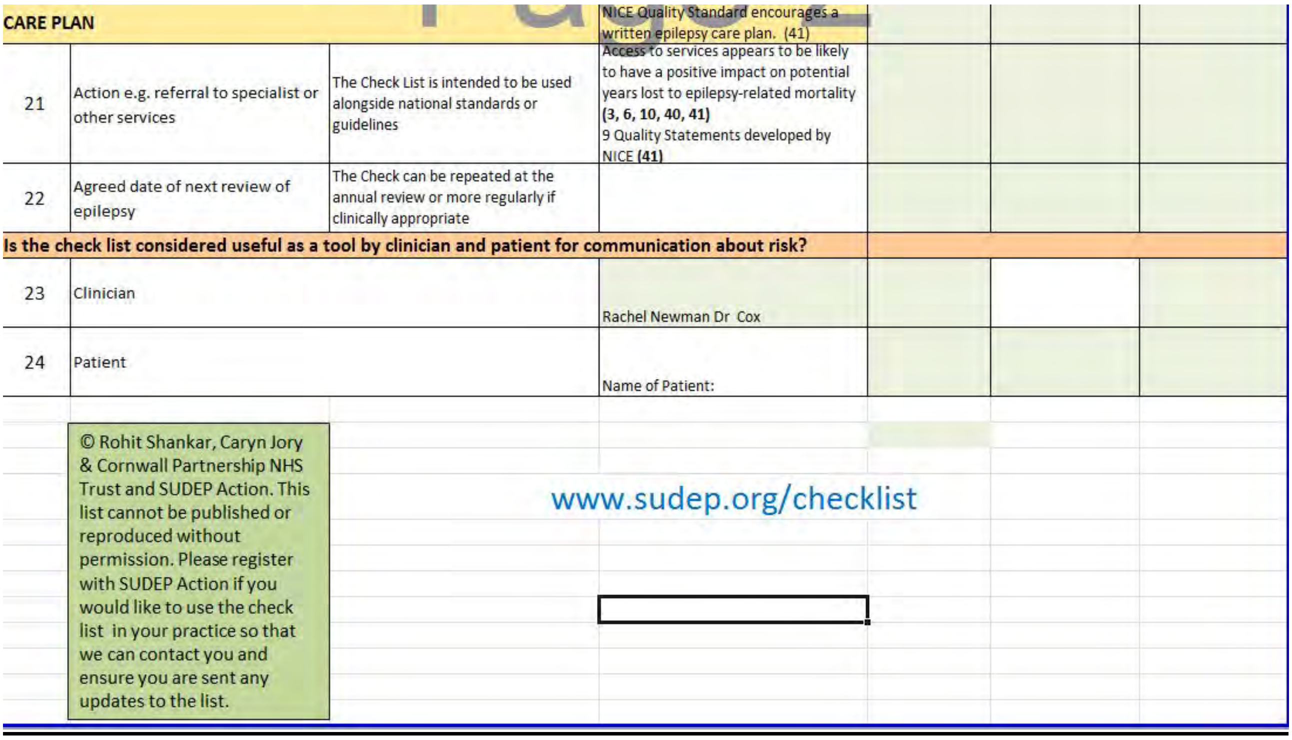
	Name of Patient:					
SUDEP AND SEIZURE SAFETY CHECK LIST -CONFIDENTIAL TO THE DEVELOPMENT GROUP				Review Results		
ID	**Risk Factor**	**Suggested Prompt**		**12/01/2017**	**dd/mm/yyyy**	**dd/mm/yyyy**
BACKGROUND						
1	Unclear seizure frequency or treatment history	Refer to patient notes. If history poor discuss with patient the benefit of regular monitoring.	Poor medical records highlighted as possible flag for risk **(3, 19, 20)**	no		
2	Duration of epilepsy more than 15 years	Refer to patient notes	Combined data from four SUDEP case-control studies found 2 fold increased risk **(21)**	yes		
3	Early onset of epilepsy before aged 16	Refer to patient notes	1.7-fold increased risk of SUDEP compared to 16-60 age group **(21, 22)**	yes		
4	Younger age	Refer to patient notes	Pooled data from SUDEP studies found most reported SUDEPS in age range 20-40 **(4)**	no		
5	Male sex	Refer to patient notes	Combined data from four SUDEP case-control studies found 2 fold increased risk **(21)**	yes		
6	Presence of intellectual disability	Refer to patient notes. Consider patient capacity and involvement of carer in discussion.	Reported finding that people with intellectual disabilities and epilepsy do have a substantially increased risk of mortality, particularly where seizures	yes		
7	Pregnancy	Is patient of child bearing age? Has she received pre-conception counselling. If pregnant review care.	Risk in pregnancy finding from reported maternal deaths **(25, 26)**	n/a		



SEIZURES						
8	Active seizures	How many seizures have you had in the last year?	Seizure freedom for 12 months found to be associated with a lower risk of mortality **(12, 27, 3)**	up to one a month		
9	Generalised Tonic-Clonic Seizures	Do you have generalised tonic-clonic seizures (GTCS)? (ie a loss of consciousness during a convulsive seizure). How many in the last 12 months?	The data on the relationship between epilepsy deaths and seizure types are limited. However, SUDEP is known to be associated with frequent GTCS **(21)**. Combined data from four case-control studies found frequent GTCS is a key risk factor for SUDEP. Increasing number of GTCS per year associated wtih statistically significant increased risk for SUDEP **(21).** Compared to people without tonic-clonic seizures, 1-2 such	4 possible		
10	Status Epilepticus / Prolonged Seizures	Do your seizures sometimes include convulsions that last longer than 5 minutes?	Status epilepticus (SE) is a prolonged seizure lasting more than five minutes, or two or more seizures within a five minute period without the person returning to normal between them. Previous definitions used a 30-minute time limit. Convulsive status epilepticus	no		
11	Nocturnal Seizures	Do you think you may have experienced a seizure during sleep? If no skip to 14	Nocturnal seizures identified as an independent risk factor for SUDEP **(19, 29, 30)**	no		



RELATED RISKS						
12	Lack of surveillance at night	What happens if you have a night time seizure?	Nocturnal supervision found to be protective in SUDEP study **(19)** Lack of supervision frequently noted when SUDEP occurred in Epilepsy Monitoring Units **(20)**	night checks and audio monitor		
13	Prone position	No question to patient advised unless considered appropriate	Systematic review highlights significant association between SUDEP and prone position **(31)**	no		
14	Injuries or use of emergency services	Have you had any injuries or ED/999 emergency service calls ?	Injuries have been identified as a risk factor for mortality **(12)**	no		
15	Medicines non-adherence issues	Do you have any difficulties taking your medication as prescribed? e.g. at times forgetting to pick up a prescription; the taste of the medication is bad; at times questioning the benefits of the medication or feeling that they need more information or support to take the epilepsy medication.	Non-adherence with AED associated with a 3 fold increase in mortality **(33)** Not collecting scripts for 91 -192 days carried a higher mortality risk **(12)** Patients seizure free with AEDs showed no excess mortality **(32)** AEDs at efficacious doses may reduce SUDEP **(34)** AED hair strand levels showed greater	no		
16	Frequent AED prescribing changes	Refer to patient notes	Frequent changes of AED dosage compared with unchanged dosage found to be a risk factor for SUDEP **(19, 35)**	no		
17	Depression or other psychiatric disorder	Have you experienced any feelings of depression, periods of low mood, or extreme sadness? Physician to note any psychatric history.	Increased mortality associated with with psychiatric comorbidity **(8, 12, 36)**	no		
18	Abusing alcohol	Do you find yourself needing alcohol daily or binge drinking?	Alcohol misuse associated with increased mortality **(12, 36)**	no		
19	Taking substances of abuse	Do you use any recreational drugs?	Substance misuse associated with increased mortality **(36)**	no		



CARE PLAN			NICE Quality Standard encourages a written epilepsy care plan. (41)			
21	Action e.g. referral to specialist or other services	The Check List is intended to be used alongside national standards or guidelines	Access to services appears to be likely to have a positive impact on potential years lost to epilepsy-related mortality **(3, 6, 10, 40, 41)** 9 Quality Statements developed by NICE **(41)**			
22	Agreed date of next review of epilepsy	The Check can be repeated at the annual review or more regularly if clinically appropriate				
Is the check list considered useful as a tool by clinician and patient for communication about risk?						
23	Clinician		Rachel Newman Dr Cox			
24	Patient		Name of Patient:			

www.sudep.org/checklist

INDIVIDUAL EPILEPSY MANAGEMENT GUIDELINES

To be completed in consultation with prescriber

Name:	**NHS No:**
Address:	**Date of Birth:**
	Phone No:
CONTACTS	
Main Carer:	**Phone No:** **Mobile No:**
GP	**Phone No:**
Specialist Doctor:	**Phone No:**
Others:	**Phone No:** **Mobile No:**

Name:	**Signature:**	**Date:**	**Date of review:**
Patient or representative:			
*** Specialist Doctor/Prescriber:**			
*** GP:**			
Epilepsy Specialist Nurse/Epilepsy Nurse:			

* *Guidelines must be signed by the Epilepsy Specialist Team, as per the shared care protocol.*

Please can you inform the Epilepsy Service –01872–000000 – as soon as possible if admitted to hospital with a seizure

Insert the below as a footer on every page of this document:

Epilepsy Management Guidelines for Jane Smith
Information correct on 01.09.16
NB. GUIDELINES ARE VOID IF ANY HANDWRITTEN COMMENTS

Seizure Descriptions

Seizure Type A

Possible Triggers

Possible warning signs

Seizure Description

Usual Duration of Seizure

Recovery

Criteria for use of magnet

At start of seizure swipe (cross) with magnet. If seizures continue for a further minute swipe again. Continue to swipe until seizure resolves and/or emergency services are contacted.

Criteria for use of emergency medication

If seizure type A lasts for 5 minutes

Or
Three type A seizures within a 20 minute period and Midazolam hasn't been administered administer at onset of third seizure

Amount of medication and route of administration
Administer 10mg oromucosal Midazolam

Midazolam 10mg (Please note Midazolam concentrations may differ. Preferred brands. Buccalam 10mg in 2mls, Epistatus 10mg in 1 ml.)

Usual reaction to emergency medication
Seizures usually settle

Total amount of emergency medication to be given for all seizure types in a 24-hour period without further medical advice.
Midazolam 10 mgs

When should emergency services be called?
If Midazolam has been given and the seizure continues for approaching a further 5 minutes.
Or
If breathing unusually affected
Or
If concerned or unsure of what action to take.

When contacting emergency services you need to say

- **I am requesting an ambulance for Jane Smith**
- **Her date of birth is 18.03.94**
- **Their address is or where you are calling from (including post code)**
- **They are having a prolonged seizure/having difficulties in breathing**
- **We have/have not administered Midazolam dose and when.**
- **You will then be given some first aid advice by the ambulance service**

Seizure Type B
Possible Triggers

Possible warning signs

Seizure Description

Usual Duration of Seizure

Recovery

Criteria for use of magnet

Criteria for use of emergency medication

When should emergency services be called?

Seizure Type C

Possible Triggers

Possible warning signs

Seizure Description

Usual Duration of Seizure

Recovery

Criteria for use of emergency medication

When should emergency services be called?

If breathing unusually affected

Or

If concerned or unsure of what action to take.

The registered manager or family member: (insert name) …………………………………..

Name:	**Signature:**	**Date:**	**Date of training:**	**Training organisation**
Joe Blogs	Joe Blogs	01.01,2013	12.12.12	CFT

To the registered manager/ named family member you have a responsibility to complete this form for your records.

This form does not need to be kept with the guidelines but may need to be shown to the prescriber of Midazolam

NHS TRUST

LEARNING DISABILITIES DIRECTORATE

BRIEF EPILEPSY PROFILE & SCREENING CHECKLIST

This tool is designed to be used under the following circumstances:

- at core assessment as applicable (if the epilepsy nursing assessment is not commenced)
- for service users on caseloads who have epilepsy, but where this is not the referred need

Completed by:

Please print name	Job Role:	Signature:	Date undertaken:

Date to be reviewed: ……………………………..

Client Information

Forenames:		**Surname:**	
Alias / known as:		**NHS No:**	
DoB:		**Medical Rec No: (if applicable)**	
Address:		**Telephone No:**	
Next of Kin:		**Telephone No:**	
Ethnic Origin		**Religion:**	
Marital Status:			
GP Name		**GP phone number:**	
GP Address:			

Epilepsy being managed by whom?	**Name & Details**
☐ General Practitioner	
☐ Learning Disability Psychiatry	
☐ Neurologist	

Is there an epilepsy diagnosis? **YES** ☐ **NO** ☐

Details:

Description of seizures (please complete one for each seizure type)

Before

During

After

Current anti-convulsant medication	**Dosage**

Rescue medication	**Dosage**	**Comment**

Is there is an epilepsy rescue medication care/ treatment plan in place?	**YES**	**NO**
Does this include: • Dose? • After how long of seizure activity should the medication be administered? • Can a second dose be administer, and when? • The maximum dose that can be given in 24 hours? • Usual reaction to medication? • When an ambulance should be called? • Under what circumstances should rescue medication NOT be administered? • When should the G.P be consulted?		

Epilepsy monitoring	**Yes/ No**	**Comment**
Are epilepsy monitoring forms in place? E.g. Unusual Monitoring form or Seizure description monitoring tool If not, share tools from toolkit as appropriate and recommendations made to take these to GP and/or neurology appointments		
Is there a record of the last Anti-Epileptic Drugs levels? If no, advise to contact prescriber		Date:
Has an epilepsy review been conducted by a medic?		Date:

RISK ASSESSMENT

Is there a current epilepsy risk assessment in place? YES ☐ NO ☐

Are epilepsy risks incorporated into the range of risk assessments in place for the person (at home, at day services, within respite care services etc.) YES ☐ NO ☐

RISK INFORMATION SHEET GIVEN TO STAFF/CARER/CLIENT (if yes, complete these details)

Signature of health care professional:

Signature of person receiving the risk information sheet:

Date:

Please note if there are any actions required following completion of this profile/screen. Consider if there are any outstanding needs to be addressed by the CLDT, and how these will be addressed. (continue on to another sheet if required)

ACTIONS	BY WHEN	BY WHOM

NHS TRUST

LEARNING DISABILITIES DIRECTORATE

EPILEPSY RISK ASSESSMENT FOR CARERS

Completed by:

Please print name	Job Role:	Signature:	Date undertaken:

Date to be reviewed: ……………………………..

Client Information

Forenames:		**Surname:**	
Alias / known as:		**NHS No:**	
DoB:		**Medical Rec No: (if applicable)**	
Address:		**Telephone No:**	
Next of Kin:		**Telephone No:**	
Ethnic Origin		**Religion:**	
Marital Status:			
GP Name		**GP phone number:**	
GP Address:			

Epilepsy being managed by whom?	**Name & Details**
☐ General Practitioner	
☐ Learning Disability Psychiatry	
☐ Neurologist	

GUIDELINE FOR COMPLETING:

Risk is an inherent process in the management of epilepsy. The nature of the condition makes risk situations inevitable. The risks to safety from having seizures will depend on the person's type of seizures; what happens to the person during a seizure; and how the person feels afterwards.

Managing risk for People with Epilepsy is concerned with reducing the likelihood of a seizure occurring, the impact that a seizure may have, and the likely consequences of a seizure during a specific activity.

For some People with Refractory Epilepsy, injury and harm is often a frequent and a distressing reality of seizures and it will be necessary to reduce the potential consequences of seizure activity. Identifying potential dangers in the home or in their daily environment will help to ensure that all reasonable steps have been taken to manage the risk associated with their seizures.

Epilepsy affects people differently; however People with Learning Disabilities who have epilepsy are subject to the same risk as those of the general population with epilepsy.

Risks can often prevent individuals from carrying out activities; therefore a balance needs to be struck between over protection and adequate safety. Some people may not want to put safety measures in place, this assessment can be used to present the risks to the Client in a way that ensures they can make an informed decision

The NICE guidelines 2012 state that all People with Epilepsy and Learning Disabilities should have a risk assessment including:

- Bathing and showering
- Preparing food
- Using electrical equipment
- Managing prolonged or serial seizures
- The impact of epilepsy in social settings
- The suitability of independent living, where the rights of the child, young person or adult are balanced with the role of the Carer.

This is a tool that can be used to identify the risk through the collation of relevant information, and/ or expertise. Action can then be taken to minimise the effect or eliminate the likelihood of occurrence.

Risk Factors

In this section identify the risk involved in the task using the guide below. Risk can then be determined by a high, medium and low scoring system.

Using the identified risk factors on the prompt sheet, individually assess the appropriateness of these, and the level of impact it may have on the individual or task.

This can be achieved using the following Guidelines:

There is a **definite** risk/ danger to the person/ others	At least weekly	**HIGH**
There is a **probable** risk/ danger to the person/ others	At least monthly	**MEDIUM**
There is a **possible** risk/ danger to the person/ others	At least yearly	**LOW**

This assessment does not replace an Occupational Therapy Environmental Assessment which may need to be considered if environmental risks are high.

1. Influences on Seizure Threshold

POINTS TO CONSIDER:

Seizure frequency, contraindications, individual triggers such as lights, temperature /infection, constipation etc. (need for further recordings)

Identified Risk Factor	**Degree of Risk**			**Notes on Action to manage Risk**
	Low	Med	High	
.				

2. Residential/ Environment

POINTS TO CONSIDER:

- Level of independence/ staffing levels
- Bedroom/ sleeping arrangement (level of bed) the use of bed alarms/ seizure alerts/ fall alarms
- Use of stairs (for some people there is a high risk of injury from falling down the stairs during a seizure**.**)
- Bathroom/ shower facilities/ toilet/ kitchen/ cooking facilities/ use of electrical/ gas appliances
- Heaters, radiators and open fires. Glass in windows, doors etc.

This assessment does not replace an Occupational Therapy Environmental Assessment which may need to be considered if environmental risks are high.

Identified Risk Factor	**Degree of Risk**			**Notes on Action to manage Risk**
	Low	Med	High	

3. Outside Environment

POINTS TO CONSIDER:

- Level of independence
- Access issues, steps
- Any other dangers e.g. ponds

Identified Risk Factor	**Degree of Risk**			**Notes on Action to manage Risk**
	Low	Med	High	

4. Daytime Occupation

POINTS TO CONSIDER:

- Level of independence, does the individual carry an alert card/ identification.
- Occupational hazards: Is an individual and specific risk assessments completed?
- Day Services: has an individual profile been shared, may there be a need for rescue medication to be administered by Staff, are Staff fully trained to administer this or is another course of action required (i.e. Ambulance).
- Ability to prepare own food/ meal
- Leisure activities

Identified Risk Factor	**Degree of Risk**			**Notes on Action to manage Risk**
	Low	Med	High	

5. Transport

POINTS TO CONSIDER:

- Is there a need for escort?
- Where is the person sat in the car, do they experience photosensitivity which may be exacerbated by car journeys on sunny days.
- Independent use of public transport. Cycling.

Identified Risk Factor	**Degree of Risk**			**Notes on Action to manage Risk**
	Low	Med	High	

6. Health Issues

POINTS TO CONSIDER:

- Contraception, menstruation, osteoporosis/ bone health.
- Sexual issues.
- Possibility of pregnancy.
- Mental health issues associated with epilepsy.

Identified Risk Factor	**Degree of Risk**			**Notes on Action to manage Risk**
	Low	Med	High	

7. Individual Needs

POINTS TO CONSIDER:

- Recognition of seizure onset, non-epileptic events, choking, cyanosis, protective headwear, level of support needed.
- Lifestyle issues and choices.

Identified Risk Factor	**Degree of Risk**			**Notes on Action to manage Risk**
	Low	Med	High	

8. Any Other Identified Risk

Identified Risk Factor	**Degree of Risk**			**Notes on Action to manage Risk**
	Low	Med	High	

References and acknowledgements:

Epilepsy Society Risk Assessments http://www.epilepsysociety.org.uk/Forprofessionals/Resourcesandtraining/ Riskassessments last accesses 02 Semptember12

Epilepsy Bereaved http://www.sudep.org/ last accesses 02 September 2012

NICE (2012). The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. www.nice.org.uk/cg137

Gloucester Partnership NHS Trust (2006) Epilepsy Risk Assessment

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RISK INFORMATION SHEET

This sheet has been designed as a prompt sheet to be shared with carers for use when completing a risk assessment.

NICE (2012) The Epilepsies guidelines state that the following risks should be assessed as a minimum:

- **Bathing and showering**
- **Preparing food**
- **Using electrical equipment**
- **Managing prolonged or serial seizures**
- **SUDEP**
- **In the social setting**

Identified Risk	**Considerations for management**
Bathing and showering	Support levels required whilst bathing Showering rather than bathing reduces risks. Use of a shower chair, safety glass or shower curtains Water temperature controls, safety 'cut-off' in the shower Levels of support required in, on and around water leisure activities (e.g. swimming, boating etc.)
Preparation of food, to include risk of choking whilst having a seizure	Support levels required whilst eating and drinking and preparing food Use of sharp knives Use of a microwave rather than a gas or electric cooker Use of cooker guards Taking plates/ dishes to the cooker rather than hot pans to the plates Adapted equipment such as tilting kettle
Using electrical equipment	Ensure there are no trailing wires attached to appliances that could cause a fire or burns if pulled over Cable tidies, available from DIY (hardware) stores, can keep wires out of the way Use of heated appliances if alone – this includes hair dryers, irons, hair straighteners and curling tongs Automatic cut-outs/circuit breakers and additional power supplies rather than multi-point plugs
Managing prolonged or serial seizures	Likelihood of prolonged seizure. There should be an epilepsy care plan in use which details what to do in a prolonged or serial seizure, and use of rescue medication if prescribed. If someone has tonic clonic seizures the use of an epilepsy pad bed alarm at night is recommended.

SUDEP - Sudden Unexpected Death in Epilepsy Factors that increase the risk of SUDEP include: • Young adults - particularly males • Learning disability • Tonic-Clonic Seizures • Nocturnal Seizures • Poor seizure control • Unwitnessed seizures (living alone) • Abrupt and frequent changes in medication • Non-compliance • Alcohol	Ensure compliance with medication. Consider use of timed dossett boxes if person self-administers Use of epilepsy pad bed monitors for anyone with tonic clonic seizures Introduce any medication changes slowly and observe for changes, and report to prescriber. Advise on sensible alcohol intake.
In the social setting	Risk assess all activities Risk of falls/use of helmet Supervision required in all water based activities Consider use of passenger assistance at train stations Ensure that rescue medication, mobile phone and support plan is taken with client when accessing community Consider use of medi alert bracelet
Environmental	Consider furniture type: no sharp corners, or furniture with glass insets Consider use of anti-suffocation pillows Consider use of assistive technology: bed pad alarms, epilepsy bracelets, timed dossett boxes, adapted mobile phones.
Other: To include driving, pregnancy, contraception	Signpost to epilepsy society for information and/or GP

FURTHER INFORMATION AVAILABLE FROM:

NICE (2012). The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary carewww.nice.org.uk/cg137

Epilepsy society http://www.epilepsysociety.org.uk/

Protocol for the Safe Bathing and Showering of People with Epilepsy

Version 1

Summary:	The risk of drowning during a seizure whilst bathing in people with epilepsy is well documented. This protocol details the recommendations which must be followed when people with epilepsy in NHS TRUST inpatient services or residential services shower or bath. It should also be used as a reference when providing advice and making recommendations to community patients with epilepsy by any healthcare professional.	
Keywords:	Epilepsy, drowning, health and social care, bathing, showering, risk assessments, capacity, evidence based practice.	
Target Audience:	All health professionals and social care staff working in NHS Trusts for information and reference. All inpatient units and social care residential accommodation fo implementation in all patients with epilepsy.	
Next Review Date:		
Approved & Ratified by:		
Date issued:		
Author:		
Director:		

Version Control

Change record

Date	Author	Version	Page	Reason for Change

Reviewers/contributors

Name	Position	Version Reviewed & Date

Contents

Appendices

(all above page numbers are applicable to individual document when printed as a separate item)

Summary of Recommendations

- It is important that people with epilepsy take extra care in a bath, because there is a risk of drowning during a seizure.
- At all times work to what is in the best interests of the person with epilepsy taking account of their personal wishes and preferences, clinical needs and capacity.
- Use the shower instead of a bath because the water runs away.
- If the person wishes to have a bath, assess their capacity to understand the risks.
- If the person does not have capacity, involve family and other relevant people in a Best Interest decision.
- Document all discussions in the person’s notes and ensure there is an up to date care plan and risk assessment regarding bathing and/or showering.
- Have somebody in the bathroom with the person with epilepsy or waiting outside the door talking to the person at all times.
- Do not lock the bathroom door. Ensure the bathroom can be accessed from outside at all times, including if the person were to fall against the door.
- Keep the water depth as minimal as possible and turn off the taps before the person enters; or, don’t put the plug in, but sit in the bath with the water running from the taps or a shower attachment.
- Ensure there is a working emergency call button or phone in the bathroom for the person and/or staff member to summon help.

1.0 Background

1.1 Epilepsy is the commonest serious neurological condition in adults, affecting around 600,000 people in the United Kingdom. Prevalence of epilepsy in the UK is 4-8 per 1000 (Shorvon, 2009). In the general population, risk of a second seizure occurring within two years of the first event is about 50% (Rugg-Gunn and Sander, 2012) but increases to nearly 100% if there is a predisposing neurological condition.

1.2 According to Bell et al. (2008) people with epilepsy have an increased risk of drowning, as high as 15 to 19 fold compared to the general population. It is therefore important that risk assessments must include bathing and showering and environments are as safe as possible (Neligan and Bell, 2015, and NICE, 2012).

1.3 Further information on epilepsy can be found in SHFT Epilepsy Map and Toolkit; SHFT, 'What to do when an inpatient has a seizure;' and National Websites such as Epilepsy Action (www.epilepsy.org), and The National Society for Epilepsy (www.epilepsysociety.org).

2.0 Purpose of Protocol

2.1 This protocol provides recommendations to assess the safety of bathing and showering for people who have epilepsy and are using NHS Foundation Trust services, (either as inpatients or within residential services).

2.2 The mandatory use of this protocol for all inpatients and residential care clients will ensure that the risk of drowning as a result of an epileptic seizure in people known to have epilepsy is fully assessed and documented to provide the best care for all our patients and clients.

2.3 Therefore, on admission to inpatient services and residential services all individuals with epilepsy must have an assessment of risk to include bathing and showering and a care plan/ support plan implemented with immediate effect.

2.4 This protocol should be transparent to all involved in the person with epilepsy's assessment and management in the bath or shower including the person, inpatient staff, support staff and their family where appropriate.

3.0 Scope

3.1 This protocol applies to all inpatient units and residential accommodation for immediate implementation in all individuals with epilepsy.

3.2 For community healthcare professionals and social care staff not providing 24 hour support and care it should be used as a reference in order to inform their assessments and recommendations for the person, family and care providers.

3.3 The information included on environmental safety and examples of ways to minimise risk in the bathroom is not an exhaustive list.

4.0 Specific Principles

4.1 The relevant general risk assessment tool for the Service must be completed on admission for TQ21 move in. In order to assess the risks to enable a person-centred care plan to be written regarding bathing and/or showering in a person with epilepsy the following factors must be considered.

<table>
<tr><th colspan="3">The Person with Epilepsy</th></tr>
<tr><td>The Individual Person</td><td>The Epilepsy</td><td>Capacity</td></tr>
<tr><th colspan="3">The Environment</th></tr>
<tr><td>General including staff factors</td><td>Bathing</td><td>Showering</td></tr>
</table>

4.2 The Individual Person with Epilepsy

4.2.1 We know epilepsy is more than having seizures and therefore the aim of this protocol is not just about preventing drowning as a result of an epileptic seizure in the bath or shower but to ensure the person with epilepsy has an increased quality of life because of the assessments and interventions they receive through NHS Trust’s services. It is important that the person feels in control of decisions made about their care and management whilst in SHFT services. Taking a person centred approach to both assessment and management ensures the person’s needs and preferences are taken into account. People with epilepsy should have the opportunity to make informed decisions about their management, in partnership with health and social care professionals. Good communication between health and social care professionals and people with epilepsy, and where appropriate families and carers, is essential.

4.2.2 Patients with epilepsy are recommended to take showers in place of baths, however all assessments and care plans must evidence that consideration has been given to personal choice and the capacity to make that choice. There may be occasions when bathing is identified as a therapeutic need, or a personal choice.

4.3 The Epilepsy

4.3.1 With just under 40 different seizure types and over 30 different epileptic syndromes, epilepsy is not a single condition. It is therefore not possible to list all the epilepsy factors related to bathing and showering. For some people their epilepsy may not present them at risk in the bath or shower, but this must never be supposed unless it has been confirmed by an epilepsy specialist (consultant neurologist; consultant neuropsychiatrist, consultant in learning disabilities with training in epilepsy).

4.3.2 The key principle is that all staff supporting individuals with epilepsy must have an awareness of the individual’s epilepsy. This would include triggers, auras, seizure warnings, seizure presentation, seizure pattern and frequency of seizures.

4.3.3 If there are triggers to seizure activity these should be avoided if possible before bathing and showering. If seizures occur at a certain time of day, the bathing routine should be adapted to maintain and increase safety. For example, if seizures occur on waking, then allowing time with the morning routine will increase safety.

4.3.4 There must be a care plan in place to state what actions staff are to take when the person has a seizure, irrespective of whether or not this is in the bath or shower.

4.4 Capacity of the person with epilepsy

4.4.1 English Law assumes that if you're an adult you are able to make your own decisions, unless it's proved otherwise. In order to make a decision it is important that the individual is provided with the information they need by the health or social care professional, in a format they can understand, and they weigh the information up to come to a decision. Finally this information must be communicated by the individual to health and social care professionals.

4.4.2 If people do not have the capacity to make decisions, professionals should follow the Department of Health's advice on consent (available from www.dh.gov.uk/consent) and the code of practice that accompanies the Mental Capacity Act (summary available from www.publicguardian.gov.uk). Staff should bear in mind that even where a patient is assessed as lacking capacity to make a decision, they should be involved as fully as possible in the decision. It is important that a Best Interest decision is made which provides minimal restriction to the individual and allows them to fulfil their wishes as far as possible. It is important that if the reason for the person's lack of capacity is temporary this is revisited at the appropriate time.

4.4.3 Capacity should be clearly documented within the individual's notes and care plan.

4.4.4 **If the individual does not have capacity** to understand and make an informed decision regarding the risks associated with bathing, a best interest decision should be made. If a best interest decision is required the appropriate people should be involved and the decision documented. Care plans should be implemented to ensure safety at all times.

4.4.5 The individual should never be left alone whilst bathing and a clear discussion regarding showering held, documented and enacted.

4.4.6 **If the individual has been assessed as having capacity and chooses to be supported to bath and shower** staff must ensure that they remain with the individual at all times.

4.4.7 **If the individual has capacity and chooses NOT to be directly supported whilst bathing and/or showering** they are entitled to make what healthcare professionals would deem as an unwise decision. However, it needs to be clearly documented that all steps have been taken to ensure the individual's capacity. Staff should have discussions with the individual on a regular basis with regards to the risk and their views. Discussions and outcomes should be documented in notes, care plans and capacity assessments.

4.5 General Environmental Principles

4.5.1 All NHS Staff supporting a person with epilepsy with bathing or showering must have completed the Trust epilepsy awareness training; be up to date with moving & handling and basic life support training.

4.5.2 Whilst the next 3 sections focus on ensuring the environmental issues, which if managed optimally, will provide as safe an environment as is reasonably practicable for all individuals, **the importance of robust individual clinical risk assessment and observation processes for people with epilepsy cannot be over- emphasised.**

4.5.3 The occupational therapy Bathing and Showering Assessment Tool can be found in appendix I and a bathroom environmental tool in appendix 2 and used when appropriate.

4.5.4 Good practice:

- Inform a second staff member of the plans to bath. Planning the routine will help if first aid response is required and will support staff confidence in the event of a seizure.
- If a second member of staff is not available. Ensure a charged phone is safely available in the bathroom to access 999.
- Ensure you have everything to hand before entering the bathroom. Have 2 extra towels to support the individual in the event of a seizure- 1st to support head, 2nd to cover and protect dignity of patient.
- Use Vacant/Engaged Sign on the door in place of locks.
- Ensure the floor space around the bath remains clear and dry.

4.6 Bathing

If a bath is chosen, or if there is no shower:

- Staff must be present at all times with the person with epilepsy in their line of sight unless there is a clear documented and risk assessed reason otherwise. If staff are not in the bathroom, they should be positioned outside the bathroom door and talking to the individual whist bathing.
- Run a shallow bath and put the water in before the person enters the bath.
- Ensure risk assessments are in place for all equipment, for example, hoists, bath seats.
- Provide a non-slip mat within the bath to avoid slipping underwater.
- Have accessible plugs attached to a secure chain or a floating plug.
- Ensure the bath drains are clean and clear of debris so they can drain quickly.
- Consider using bath pillows and side cushions to offer protection from the sides of the bath. These should be provided as part of a full assessment by an occupational therapist with a clear care plan in place for their use.
- Adjust any environmental factors such as lighting, noise and heat that may trigger a seizure.
- Ensure any mechanical baths have been serviced in line with manufacturers/ SHFT recommendations.

4.7 Showering

4.7.1 Having a shower can be safer than having a bath. However it does not totally eliminate all risk of injury and possible fatality. Consider the following:

- Keep drainage free from debris and running freely.
- Level access showers provide easier access, reduce the number of hard surfaces to fall against, such as the side of a bath, and does not allow the water to build up unlike a shower tray.
- A shower curtain, rather than a screen or door, makes it easier to reach someone quickly if they have a seizure in the shower, and prevents the risk of injury during a seizure.
- A fitted seat with protective covering or a padded shower chair may help reduce injury as the distance to fall is reduced.

5.0 What to do in the event of a seizure

- Shout loudly and clearly for help and keep shouting until it arrives.
- Activate the call button/emergency alarm or if in a residential care setting and alone consider dialling 999. 999 should be called immediately if there is concern of injury or staff feel unable to manage the seizure.
- Remain calm and reassure the individual by talking quietly and calmly.
- If a hoist and sling is being used, follow the individual's risk intervention plan.
- Support the individual's head above the water.
- Check the time if possible.
- Remove the plug and allow the water to drain. Place a towel under the persons head if required to avoid any injury.
- Use a second towel to cover the person and continue to call for help.
- Allow the person to continue with the seizure.

  DO NOT MOVE THE INDIVIDUAL OUT OF THE BATH/SHOWER UNTIL THE SEIZURE ENDS.

- Check the time when the seizure ends.
- Administer Emergency Medication in line with prescribed protocol if required.
- Call 999 if the seizure becomes prolonged, if an injury has occurred or other concerns are raised (Nice guidelines states to call 999 after five minutes).
- If emergency services are needed, allow the second member, if present, to alert 999 and respond whilst the first staff member continues to support the person and offers reassurance.
- Once the water has been drained, cover with towels, blankets or clothing to maintain body temperature, which will be lost quickly following a seizure.
- Place in the recovery position out of the bath after the seizure has finished.
  Continue to keep the individual warm with covers.
- Follow the person's epilepsy care plan.

5.1 If resuscitation becomes necessary, as the person has stopped breathing, the National Resuscitation Council (UK) guidelines (2015) should be followed. These guidelines state that the person, "*who is unresponsive and not breathing normally is in cardiac arrest and requires CPR. Immediately following cardiac arrest blood flow to the brain is reduced to virtually zero, which may cause seizure-like episodes that may be confused with epilepsy. Bystanders and emergency medical dispatchers should be suspicious of cardiac arrest in any patient presenting with seizures and carefully assess whether the victim is breathing normally*".

6.0 Recording and post seizure

6.1 When writing care plans, as a result of the risk assessment, clinical discussion, discussion with the patient, family and relevant parties, capacity decision etc. the following **MUST** be included:

- Choice and capacity.
- The level of staff support that the individual requires to keep them safe whilst bathing or showering.
- Any factors that may impact (increase or decrease) risk.

6.2 Following the individual suffering a seizure:

- Complete all recording charts and documentation in line with Trust policy.
- Complete a Ulysses entry when a seizure occurs in the bath or shower.
- Report seizures in a bath to the Senior in Charge and discuss whether there needs to be a change in bathing or showing care plan. In addition, this must also be discussed at the next MDT meeting within a week if the person with epilepsy is an inpatient.
- Ensure information is provided within shift handover.
- Consider referring the person for review of their epilepsy to the GP, consultant psychiatrist or consultant neurologist if the seizure is unusual or there are concerns from staff.

6.3 This is not an exhaustive list of actions and individual health and social care professionals should use their professional knowledge, skills and training to ensure any other appropriate actions are taken. If an individual is not confident with supporting a person with epilepsy it is their responsibility to ensure their line manager is aware of their concerns.

7.0 References

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8.0 Acknowledgements

Epilepsy Society Keeping Safe at Home http://www.epilepsysociety.org.uk/keeping-safe-home

Appendix 1

OCCUPATIONAL THERAPY - BATH / SHOWER ASSESSMENT TOOL	
Name:	**Date of Birth**
Address:	**Telephone number:**
GP's Name/Address/Telephone No:	**NHS Number:**
CONSENT: **Has the reason for the bathing assessment been explained?** **Has the client given informed consent?** **Is a best interest decision necessary?**	**Yes / No*** **Yes / No*** **Yes / No***
HEALTH **Diagnosis:** **Medication / reported side effects:** **Epilepsy:** ***If yes, state type, frequency, pattern, warnings, past injuries sustained*** **Sensory Impairment:** ***For example, visual impairment*** **Energy Levels** ***For example, fatigue, hyperactive*** **Continent** ***If no, detail, including skin integrity, bathing medical needs, wounds***	**Yes / No *** **Yes / No *** **Yes / No *** **Yes / No ***

ENVIRONMENT **Ward/ Own home/Residential care/Supportive living etc.** **If community – who does the patient live with and support available:** **Location of, access to and description of Bathroom and shower room** ***For example, size, flooring, shower/ bath, location of bathing suite, hazards, clutter*** **Aids used at time of assessment:** ***For example, shower chair, bath seat, hoist, bath lift, grab rails***	
VOLITION ***For example, is this a valued activity, is the client motivated, client's preference for bath/shower, ability to make choices.***	
ROUTINE - BATHING/SHOWERING ***For example, frequency, time of day, is there a specific routine***	
OCCUPATIONAL PERFORMANCE - **BATHING/SHOWERING** **Independent / Requires minimal or moderate support / Dependent***	
Gross motor skills affecting bathing/showering ***For example, mobility, transfers*** **Fine Motor Skills affecting bathing/showering** ***For example, holding soap, flannel***	

Sensory Skills affecting bathing/showering ***For example, vision, tactile, vision, lighting*** **Cognitive and Perception Skills** ***For example, logical sequencing, depth awareness***	
COMMUNICATION ***For example, how does the client communicate, does the client understand what is being asked.***	
RISKS IDENTIFIED **AT TIME OF ASSESSMENT**	
RECOMMENDATIONS ***Such as, personal care assessment / skills teaching, adaptations, compensation techniques***	
OT PLAN	
Occupational Therapist: **Date:**	**Cc: Client** **GP** **Primary Nurse** **Client's notes**

Appendix 2 Bathroom environmental checklist

HOME SAFETY	OT Advice	Comments	Points to consider
Bathroom			
Flooring			Risk of impact damage from falls on to ceramic and quarry tiles. Cushioned, non-slip flooring is preferable. Any loose edged tiles.
Radiators			To be covered. Helps avoid risk of injury from sharp corners / contact burns / impact with rigid surface
Shower			For people with active seizures, a level access shower is the safest option. Where client prefers a bath, he/she must be informed of risks and a risk assessment completed.
Shower seat			Reduces risk of injury from falling when standing. Shower chair should be padded, protection cover is needed for wall fitted shower seats.
Thermostatic control of hot water flow			A thermostat can be fitted to prevent the hot water from raising above a certain temperature, to reduce the risk of scalds
Taps with safe profile			Rounded taps are preferable. Cross headed and level taps are not recommended because they can cause gouging injuries in falls. Taps can be covered with a towel to soften the surface.
Bath			Bath lift or padded bathing cushions may be needed. Refer to OT for a full assessment.
Exposed pipes to be lagged or boxed in			Lessens the risk of burns from exposed hot pipes.
Hand rails / grab bars			May be needed and if so, padded grab rails are recommended, in a colour that contrasts against the wall. Refer to OT.
Access to the bathroom - Doors			Outward opening, sliding or concertina door gives full access in an emergency.
Socket covers, e.g. for shaver socket			These protect against risk of electrocution; important where there is risk of random automatic behaviour in complex partial seizures
Locks			Good window locks and external door locks reduce risk of lack of security during seizure activity. To increase safe access, engaged signs to be used instead of locks or locks that are double accessed.
Other, for example, mirrors, windows			Consider the glass in the environment – are mirrors Perspex, are windows double glazed. Containers, fixed objects protruding from the walls, such as soap dishes, sharp edges, washbasin shape, clutter.

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COMMUNITY EPILEPSY EMERGENCY MANAGEMENT PLAN FOR USING MIDAZOLAM

This is current care plan for XXX

Dated:

Please note that this is a pathway only for use in the community.
Acute hospital to follow hospital clinical policy

If XXX fails to respond & requires hospital admission, please ensure you take this care plan with you, their current Mars sheet and a copy of their Consultants latest clinic letter as it details their epilepsy treatment plan

Name **Address** **Postcode** **Date of Birth** **NHS No:**			
Date completed:		**Completed by:**	
Review Date:			
Medication: **Prescribed dosage:** **Route of administration:** **Maximum Dose in 24hrs**	Midazolam 10mgs Intranasally **10mgs in 24hrs for community setting only, but in Hospital at the discretion of doctor's higher doses may be used.**		
To be given in the following circumstances	Midazolam 10mgs given for		
If the seizure doesn't stop having given the prescribed dose of Midazolam act as follows:	• If seizure continues following ---- dose of Midazolam 10mgs for a further 5 minutes **dial 999** and seek urgent medical assistance. • If you are concerned about XXX at any time Dial 999. • **Please do not contact CLDT for emergency support**		
What to do if you cannot give Midazolam.	If you are unable to administer midazolam for any reason • Ensure XXX safety • **Dial 999 for Emergency medical assistance** • As soon as emergency services have been contacted and person's safety is ensured then document in notes reasons for difficulty in giving • Once emergency has been dealt with notify GP and at a later point when convenient inform the Consultant/Community Nurse		
DO NOT GIVE MIDAZOLAM IF:	• XXX has already had Midazolam --mgs in 24 hours Dial 999 • XXX has a fall and hits their head dial 999 • XXX vomits dial 999 • Staff feel they do not have the skills/competence or are unconfident to administer midazolam Dial 999 • Midazolam should **ONLY** be used in line with this care plan		
Possible adverse reaction to Midazolam could be	Significant changes in breathing, colour or **ANY CONCERNS** Dial 999		

- **Please see separate flow chart attached**

Midazolam is unlicensed for use in adults with epilepsy and is currently (Oct 2009) a class 3 controlled drug according to the Misuse of Drugs Regulations (2001).

Therefore if it is lost or stolen the police and CQC should be informed, it should be locked away and stored as advised by the pharmacist and any suspected reactions reported to the Doctor. Please dispose any unused medication as per your local guidelines/company policy and record all occasions when Midazolam is administered must be recorded.

CONSENT

- Has consent to this rescue plan been obtained?
- Does XXX have the capacity to consent to this rescue plan?

Please add statement re capacity:

XXX lacks the capacity to consent to his/her care and treatment, including the administration of medications so they are offered to him/her **in his/her Best Interests.**

If no, has this procedure been agreed as in the individual's Best Interest by the multi-disciplinary team? **YES**

This Plan has been agreed by the following:

Prescribing Doctor (GP) Name: Dr

Address: Health Centre

Signature ……………… Date …………

Recommending Doctor: Name: Dr

(Consultant) Address:

Signature ……………………… Date ……………

Community Nurse: Name

Address:

Signature …………………… Date ……………

Parent/Carer/Guardian/

Registered Manager: Name

Address:

Signature ……………………… Date ……………

<u>Please only keep a copy of current care plan</u>

<u>Discontinue and archive any old plans</u>

Community Epilepsy Emergency Management Plan Flowchart for using Midazolam for XXX

Medication – **Intranasal Midazolam 10mg (one 2ml ampoule)**

Type A or B or D begins

Note time & continue observing XXX Ensure they remain safe

Seizure continues for 5 minutes with no recovery

XXX does not respond to stimulus (i.e. saying their name)

Administer Intranasal Midazolam 10mgs

Continue observing

If you cannot administer Midazolam for any reason:

- **Ensure XXX is safe & dial 999**
- As soon as possible document reasons for not administering in notes
- Once emergency has been dealt with and it is possible, inform Consultant/Community Nurse

If the seizure does not stop for 5 minutes after giving Midazolam:

- **Dial 999** immediately
- **Do not contact CLDT for emergency support**
- **If ---- deteriorates or if you are concerned after giving Midazolam contact emergency services immediately by dialling 999 (i.e. drowsiness, breathing problems)**

- **Do not give Midazolam if has already been given --mgs within the last 24 hours or staff are untrained to administer – Dial 999**
- If XXX has a fall and hits their head – Dial 999
- If XXX vomits during seizure – Dial 999

PROTOCOL FOR THE ADMINISTRATION OF RESCUE MEDICATION

INCLUDING:

INTRANASAL MIDAZOLAM

ORAL LORAZEPAM

ORAL CLOBAZAM

FOR

NAME:

ADDRESS:

DOB:

xxxxx has a number of difference seizures and in different circumstances he/she is prescribed different rescue medication to treat these breakthrough seizures.

TONIC CLONIC SEIZURES

- TONIC CLONIC seizures are the ones where XXXX loses consciousness, falls to the floor if standing, slumps in a chair if seated and first becomes stiff. After the stiffness, he/she then goes on to have shaking of his/her limbs. The shaking is rhythmic and the movements although initially small will become greater until they stop. These seizures are a great concern as they can lead to further disability in the long term, and, in the past, XXXX has had prolonged generalised TONIC CLONIC seizures which have resulted in him/her being admitted to hospital. Because of this, every time XXXX has a TONIC CLONIC seizure, he/she is administered rescue medication.

- **If a TONIC CLONIC seizure occurs administer 10mg (2ml) MIDAZOLAM intranasally.**

If there is still no recovery after 5 minutes call an ambulance, always state that we need 3-4 paramedics to lift and support XXXX as he/she is of a large build.

- If XXXX has come out of a seizure after one dose of MIDAZOLAM and shortly has another TONIC CLONIC seizure he/she can be administered a second dose of MIDAZOLAM. If he/she then goes on to have another TONIC CLONIC seizure then paramedics and/or the doctor must be called.

Do not give a third dose of MIDAZOLAM without seeking professional advice i.e. phone On-Call Doctor on 01453 764222

- Record the administration of MIDAZOLAM on the sheet

- XXXX should not have more than 20mgs of MIDAZOLAM in 24 hours without the support of his/her GP (or the on call GP)

COMPLEX PARTIAL SEIZURES

- COMPLEX PARTIAL seizures are the ones where XXXX will become vacant for a few seconds, will sometimes pick at his/her clothing or stutter over his/her words and will be unable to follow commands for a few seconds. When it has gone over he/she may be able to carry on with what he/she was talking about before it started or carry on with the activity he/she was performing before it happened.

- XXXX is now seemingly having many more of these sorts of seizures than the TONIC CLONIC seizures.

- Sometimes, XXXX can have a number of these smaller seizures in a row and this can affect his/her ability to communicate and has, in the past, left him/her unable to perform his/her activities of daily living.

- Although these seizures can be very debilitating, they are not clearly associated with long term disability but do need his/her long term, regular antiepileptic drugs (AED's) reviewed and are the reason for the introduction of his/her newer antiepileptic medication.

CLUSTER SEIZURES

Definition:

- XXXX sometimes has repeated COMPLEX PARTIAL seizures which are not usually prolonged. When he/she has one he/she may have a number and sometimes he/she may have so many that it is difficult for him/her to communicate or carry out his/her personal care. **These are called CLUSTER seizures.**

- If XXXX has a seizure and is able to take his/her oral rescue medication this should be administered immediately as prescribed, this is called LORAZEPAM.

- The LORAZEPAM is given to him/her to prevent further seizures. It is a longer acting drug, takes about half an hour to be absorbed (so should start working then) and is in the system for about 8-12 hours (and so should work for that long).

PROTOCOL FOR ADMINISTRATION OF RESCUE MEDICATION

- XXXX can have clusters of COMPLEX PARTIAL SEIZURES if they are not prolonged and he/she wakes up between them, but they are happening more than once a day, XXXX should have LORAZEPAM 2MG. If XXXX continues to have COMPLEX PARTIAL SEIZURES despite LORAZEPAM 2mg he/she can have a second dose in 24 HRS.

- If XXXX has needed 2 doses of LORAZEPAM in 24hrs and requires a further dose the next day, he/she should have CLOBAZAM 10MG at NIGHT for 5 DAYS.

- If he/she has had LORAZEPAM and then goes on to have a prolonged TONIC CLONIC SEIZURE, he/she should be given nasal MIDAZOLAM as prescribed. If this seizure continues for longer than 5 minutes follow instructions on page 1 as he/she has had 2 doses of rescue medication.

Remember do not administer a 3rd dose of Midazolam without seeking advice

Reviewed by Dr XXX on

To be reviewed 6 monthly - next review on or before.

AFTER CARE, SIDE EFFECTS AND OBSERVATIONS FOR MIDAZOLAM

Side effects

Can include changes to breathing pattern, decrease in blood pressure, headache, dizziness and hiccoughs.

It is quite normal for xxxx to sneeze after having Midazolam administered; this may sometimes result in him having a mild nose bleed.

Observations

Observe breathing carefully and check for evidence of cyanosis e.g. bluing around the lips and fingertips. If you are concerned about XXXX's breathing at any time call an ambulance.

If XXXX is ambulant and walking around, he will need to be observed closely as he may experience dizziness or a drop in blood pressure, which may lead to a fall.

XXXX may be disorientated on waking and will require reassurance.

Do not give XXXX anything to eat or drink until he has fully recovered

Epilepsy Care Plan

Personal details	Name	
	DoB	
	NHS No	
	Address	
	Next of Kin	
	GP Name, address, Phone	
	Specialist involved	
	Last Appointment	

Medical Information	Date epilepsy diagnosed	
	Syndromes / seizure type	
	Seizure description	
	Usual seizure length / recovery	
	Current medication	
	Previous medication and reason stopped	
	Triggers for seizures	

Seizure first aid Plan	What to do during a seizure	

Emergency Epilepsy Plan	What constitutes an emergency?	
	Prolonged seizures	Rescue medication plan
	Repeated seizures	Rescue medication plan
	Non-convulsive seizures	Rescue medication plan
	When to call an ambulance	

Current treatment plan	Rationale for treatment	
	Drugs to be avoided	
	Changes to treatment in the event of an emergency admission	
	Date started	
	Date for review	

Risk Assessments		

Others involved	Name and address	
	Relationship	

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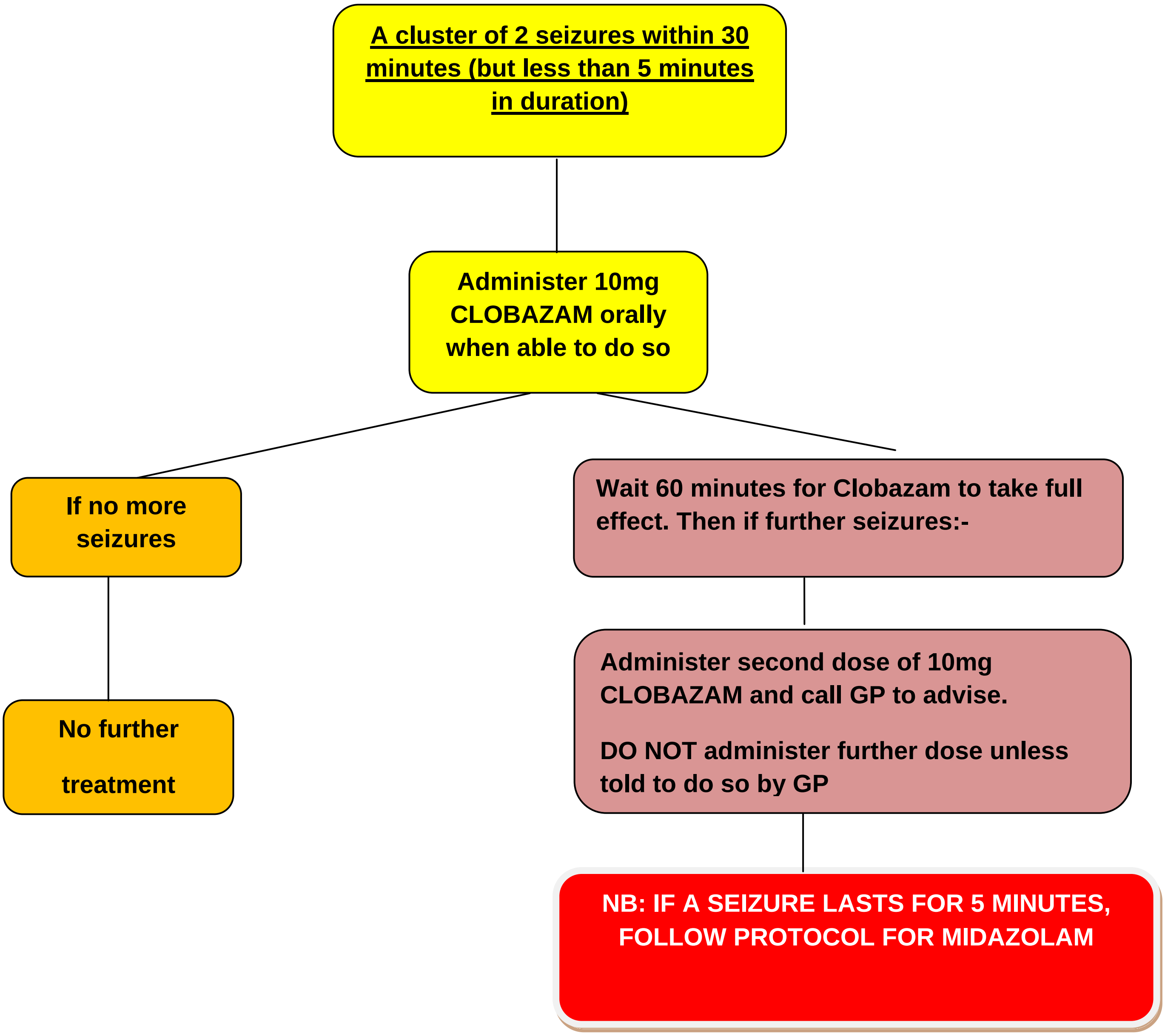
CLOBAZAM ADMINISTRATION PROTOCOL

ENSURE XXX HAS RECOVERED FROM SEIZURE BEFORE ADMINISTERING ORAL MEDICATON



A cluster of 2 seizures within 30 minutes (but less than 5 minutes in duration)

Administer 10mg CLOBAZAM orally when able to do so

If no more seizures

No further treatment

Wait 60 minutes for Clobazam to take full effect. Then if further seizures:-

Administer second dose of 10mg CLOBAZAM and call GP to advise.

DO NOT administer further dose unless told to do so by GP

NB: IF A SEIZURE LASTS FOR 5 MINUTES, FOLLOW PROTOCOL FOR MIDAZOLAM

Following administration of CLOBAZAM please follow PRN guidelines as below;

Day 1 (day of cluster)	Clobazam protocol to be followed as above
Day 2	Administer 1 **additional** 10mg CLOBAZAM at 9pm
Day 3	Administer 1 **additional** 10mg CLOBAZAM at 9pm
Day 4 and onward	Return to normal prescribed daily dose

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NHS TRUST

LEARNING DISABILITIES DIRECTORATE

EPILEPSY NURSING ASSESSMENT

Completed by:

Please print name	Job Role:	Signature:	Date undertaken:

Date to be reviewed: **……………………………..**

Peer Reviewed:

Completed by (please print name)	Job Role:	Signature:	Date undertaken:

CONFIDENTIAL

Not to be disclosed without prior discussion with, and permission from the Author

Client Information

Forenames:		**Surname:**	
Alias / known as:		**NHS No:**	
DoB:		**Medical Rec No:** **(if applicable)**	
Address:		**Telephone No:**	
Next of Kin:		**Telephone No:**	
Ethnic Origin		**Religion:**	
Marital Status:			
GP Name		**GP phone number:**	
GP Address:			
Epilepsy being managed by whom?		**Name & Details**	
☐ **General Practitioner**			
☐ **Learning Disability Psychiatry**			
☐ **Neurologist**			
Social Worker / Key Worker / Others involved?			
Social Situation			
Information for this assessment has been gathered from the following sources:			

Reason for referral:

Does the service user have capacity to understand, and agree to the referral?

All diagnoses (including epilepsy)	By whom	Date of onset (if known)
▪ ▪ ▪ ▪ ▪ ▪		

Status Epilepticus

Convulsive status Yes ☐ No ☐ date of first occurrence…………………

date of last occurrence…………………

Non convulsive status Yes ☐ No ☐ date of first occurrence…………………

date of last occurrence…………………

Is rescue medication prescribed? Yes ☐ No ☐

Are there rescue medication guidelines that have been written or reviewed within the last year? Yes ☐ No ☐

Current Medication (please list ALL medications here):

Medication	**Date**	**Dose**	**Frequency**	**Date Started**

Previous anti-epileptic medications:

Previous drug	Date commenced	Max dose	Dose stopped	Reason for discontinuation (Allergies, interactions side effects)
▪				
▪				
▪				
▪				
▪				
▪				
▪				
▪				
▪				
▪				

Any known allergies Yes ☐ No ☐ details……………………………..

EPILEPSY SURGERY

Type of surgery	Date performed	Name of hospital	Surgeons name	Comments/ Instructions

INFORMATION ON ANY OTHER EPILEPSY TREATMENT

Date	Treatment Tried	Outcome

HISTORY

Communication:

How does the person communicate their needs - Please specify

Family History:

Known ☐ Unknown ☐

Do other members of the family suffer from of have suffered from epilepsy?

Developmental history

Known ☐ Unknown ☐

Gestational period …………………… Birth Weight………………………….

Type of delivery (any complications).………………………………………...................................

Syndrome diagnosed:…………………………………………………………………...

Febrile convulsions: Yes ☐ No ☐

First seizure

Age of onset and description

INVESTIGATIONS

Please complete for the **three most recent EEG's** (enclose copies of reports if available)

	1	2	3
Date			
Place			
Results			

CT/ MRI Scan results

	1	2
Date		
Place		
Results		

Blood tests

Date	Relevant Blood test	Result
	. . .	

Details of other investigations (e.g. assessment at Chalfont Centre)

Date	Investigation	Result
	. . .	

PHYSICAL HEALTH

Have any swallowing problems been identified? YES ☐ NO ☐

Are there any problems taking medication? (consider if liquid medication is necessary)

Current weight ……………… Height ……………… BMI ………………

Maintaining weight YES ☐ NO ☐

Unintentional weight LOSS ☐ GAIN ☐

Intentional weight LOSS ☐ GAIN ☐

Are there any concerns regarding weight changes as a side effect of medication?

	Yes	**No**	**unknown**	**Details**
Does the person have support over night?				
Does the person have a disturbed sleep pattern?				
Are they awake much of the night?				
Does the person move around in their sleep (that is they wake in a different position to that they went to sleep in)?				
Do they sleep much of the day?				
Is a bed alarm or any Telecare device used?				

TRIGGERS

Are there any known triggers to seizures?

	Yes	No	Details
Sleep deprivation			
Illness/ infection/temperature			
Strobe lighting or flashing lights			
Pain			
Changes to medication (AED or otherwise)			
Poor concordance			
Catamenial (linked to menstrual cycle)			
Constipation			
Stress			
Activities/ Events			
Alcohol			
Others			

Is there a particular time of day that seizure activity is more likely?

SEIZURE DESCRIPTION – Type XXX

Please complete one set of these three recording sheets for **ALL** seizure types, including as much information as possible about their typical presentation ***before*** seizure, ***during*** seizure and ***after*** seizure. Further sets of descriptions may be required if several seizure types are evident.

BEFORE

Is the person able to describe or have Carers observed any of the following:

	Yes	**No**	**Details**
An identifiable Aura or warning?			
Automatisms?			
Restlessness?			
Change in mood/ emotion?			
Change in behaviour?			
Unusual sensation such as strange taste or smell?			
Any weakness, numbness or pins and needles. If so where?			
Any visual disturbances?			
Any unusual gastric sensations			
Any unusual noises such as crying out or mumbling			
Any further details not covered			

DURING

	Yes	**No**	**Details**
Do they lose consciousness, if so for typically how long?			
Do they fall - if so forward, backward or straight down? - Do they go stiff or floppy			
Does their colour change - If so, do they become pale or flushed? - Do they become cyanosed?			
Does any part of their body move? - If so, what parts? - What sort of movements are they (e.g. convulsive, jerks, shudders?			
Does there head turn, if so which way?			
Is there any head turning, facial grimaces, chewing movements or lip smacking?			
Do their eyes stay open or do they close? - do their eyes turn to one way? - do their eyelids flutter? - do they go blank and stare?			
Does their breathing change? - does it become noisy or laboured? - does it become fast? - do they ever stop breathing?			

During continued

	Yes	No	Details
Do they do anything unusual such as pick at objects or fiddle with clothing?			
Are there any strange behaviours exhibited?			
Is there ever incontinence of urine or faeces?			
Any further details not covered			

AFTER

	Yes	No	Details
Are they able to describe how they feel after a seizure?			
Are they able to recover and carry on as normal?			
Do they show signs of confusion, if so, for how long?			
Do they become agitated, restless?			
Do they need to sleep, if so, for how long?			
Do they experience headache or tiredness?			
How long does it take to fully recover?			
Any further details not covered			

SEIZURE DESCRIPTION – Type XXX

Please complete one set of these three recording sheets for **ALL** seizure types, including as much information as possible about their typical presentation ***before*** seizure, ***during*** seizure and ***after*** seizure. Further sets of descriptions may be required if several seizure types are evident.

BEFORE

Is the person able to describe or have Carers observed any of the following:

	Yes	**No**	**Details**
An identifiable Aura or warning?			
Automatisms?			
Restlessness?			
Change in mood/ emotion?			
Change in behaviour?			
Unusual sensation such as strange taste or smell?			
Any weakness, numbness or pins and needles. If so where?			
Any visual disturbances?			
Any unusual gastric sensations			
Any unusual noises such as crying out or mumbling			
Any further details not covered			

DURING

	Yes	No	Details
Do they lose consciousness, if so for typically how long?			
Do they fall - if so forward, backward or straight down? - Do they go stiff or floppy			
Does their colour change - If so, do they become pale or flushed? - Do they become cyanosed?			
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Does their breathing change? - does it become noisy or laboured? - does it become fast? - do they ever stop breathing?			

During continued

	Yes	No	Details
Do they do anything unusual such as pick at objects or fiddle with clothing?			
Are there any strange behaviours exhibited?			
Is there ever incontinence of urine or faeces?			
Any further details not covered			

AFTER

	Yes	No	Details
Are they able to describe how they feel after a seizure?			
Are they able to recover and carry on as normal?			
Do they show signs of confusion, if so, for how long?			
Do they become agitated, restless?			
Do they need to sleep, if so, for how long?			
Do they experience headache or tiredness?			
How long does it take to fully recover?			
Any further details not covered			

SEIZURE DESCRIPTION – Type XXX

Please complete one set of these three recording sheets for **ALL** seizure types, including as much information as possible about their typical presentation ***before*** seizure, ***during*** seizure and ***after*** seizure. Further sets of descriptions may be required if several seizure types are evident.

BEFORE

Is the person able to describe or have Carers observed any of the following:

	Yes	**No**	**Details**
An identifiable Aura or warning?			
Automatisms?			
Restlessness?			
Change in mood/ emotion?			
Change in behaviour?			
Unusual sensation such as strange taste or smell?			
Any weakness, numbness or pins and needles. If so where?			
Any visual disturbances?			
Any unusual gastric sensations			
Any unusual noises such as crying out or mumbling			
Any further details not covered			

DURING

	Yes	No	Details
Do they lose consciousness, if so for typically how long?			
Do they fall - if so forward, backward or straight down? - Do they go stiff or floppy			
Does their colour change - If so, do they become pale or flushed? - Do they become cyanosed?			
Does any part of their body move? - If so, what parts? - What sort of movements are they (e.g. convulsive, jerks, shudders?			
Does there head turn, if so which way?			
Is there any head turning, facial grimaces, chewing movements or lip smacking?			
Do their eyes stay open or do they close? - do their eyes turn to one way? - do their eyelids flutter? - do they go blank and stare?			
Does their breathing change? - does it become noisy or laboured? - does it become fast? - do they ever stop breathing?			

During continued

	Yes	No	Details
Do they do anything unusual such as pick at objects or fiddle with clothing?			
Are there any strange behaviours exhibited?			
Is there ever incontinence of urine or faeces?			
Any further details not covered			

AFTER

	Yes	No	Details
Are they able to describe how they feel after a seizure?			
Are they able to recover and carry on as normal?			
Do they show signs of confusion, if so, for how long?			
Do they become agitated, restless?			
Do they need to sleep, if so, for how long?			
Do they experience headache or tiredness?			
How long does it take to fully recover?			
Any further details not covered			

INJURY RESULTING FROM EPILEPSY

Has the person ever sustained injury as a result of seizure activity? YES ☐ NO ☐

Frequency of occurrence

	Seizure type (from above descriptions)		
	1	**2**	**3**
Never			
Rarely			
Often			
Every seizure			

Most common site of injury

	Seizure type		
	1	**2**	**3**
Head/face			
Arms			
Legs			
Other (please state)			

Is protected head gear prescribed? YES ☐ NO ☐

Is it worn at all times? YES ☐ NO ☐

If prescribed but not warn at all times is there a risk assessment? YES ☐ NO ☐

Most recent hospital admission/ attendance						
	Date	LOS★	Date	LOS★	Date	LOS★
For epilepsy						
For injuries						

★= Length of stay

ACTION PLAN

Please indicate what support will be offered following assessment (The following are only suggested needs, individualised ones may well be identified).

This does not negate the need for Nursing Care Plan

Identified Needs	**Action/ who is responsible**
Further investigation into seizure classification/ pattern/ triggers?	
Introduce appropriate monitoring/ recording documentation.	
Referral for medication/ treatment review?	
Support with medication changes (including concordance with medication)	
Full risk assessment/ management plan required?	
Referral for Telecare?	
Rescue medication guidelines required?	
Education/ Training for Client/ Carers?	
Support with psychosocial issues?	
Information about quality of life issues required?	
Referral onto other health professionals?	
-	
-	

References:

NICE (2012). The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. www.nice.org.uk/cg137

Epilepsy Society - http://www.epilepsysociety.org.uk/aboutepilepsy/firstaid/recordinginformationaboutseizures last accessed 02 September 2012

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Anti-Epileptic Drugs Competency Sign Off Sheet

This list of questions has been developed to be used as an addendum to the LD Nursing Medicine Competency Toolkit. Please complete with your supervisor/manager/mentor and add to your medicine competency toolkit.

Name of Nurse…………………………………………….. **Name of Manager ……………………………………..**

Competency	Evidence	Date	Manager Signature	Nurse Signature
Can identify specific changes in seizure presentation that could signal problems, and can discuss these with the prescribing clinician.				
Can use current national guidelines (mainly NICE guidance) in relation to anti-epileptic drug treatment and can assess and monitor for efficacy and side effects during new drug titration.				
Can describe which tests are required and when, for patients prescribed anti-epileptic medication.				
Can assist in the formulation of an epilepsy rescue medication formulation plan in line with Trust policy where appropriate, including the provision of training.				
Can complete risk assessments which identify anti- epileptic medication associated risks as listed in national guidelines and advise on further intervention if required.				
Can identify the gaps in knowledge of patients and carers and provide adapted information, resources and individualised training to increase medication compliance and optimise the patient’s quality of life.				
Can respond appropriately to seizure activity and implement/review the medicines related care plan as necessary.				
Can discuss the use of epilepsy rescue medication as per treatment plan, including potential side effects.				
Can identify and discuss the typical side effects of the main first line and second line anti-epileptic drugs as listed within the BNF.				
Can identify the drugs which require specific precautions because of the known contraindications.				

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Glasgow Epilepsy Outcome Scale

(GEOS 35)

Name of person with epilepsy ………………………………………………

Outcome scale competed by ………………………………………………

Role/ relationship to person ………………………………………………

Date of completion ………………………………………………

Please complete this with the Carer of the person with epilepsy to assess ***their*** concerns that they have with regards to the person they care for.

Focus only on the named individual, and the impact that their epilepsy rather than their learning disability has on their life.

Remember that the scale is trying to assess concern about each item, not if they believe the item to be true.

Please mark the response which best represents their level of concern ***during the last three months,*** using the following rating scale:

0	Never a concern/ not applicable
1	Only occasionally a concern
2	Fairly often a concern
3	Often a concern
4	Very often a concern

A. CONCERNS ABOUT SEIZURES

Seizure event

I am concerned about the person’s epilepsy because…

1	The pattern of seizure activity changes all the time	0	1	2	3	4
2	They have seizures every day	0	1	2	3	4
3	It is not possible to stop the seizures	0	1	2	3	4
4	They have one seizure after another	0	1	2	3	4
5	They may choke during a seizure	0	1	2	3	4
6	The carer has to act quickly during a life threatening seizure	0	1	2	3	4
7	They fall down during seizures	0	1	2	3	4

After effect of the seizure

8	The person’s epilepsy causes behaviour problems	0	1	2	3	4

I am concerned that after the seizure the person with epilepsy…

9	Is floppy and unresponsive	0	1	2	3	4
10	Is confused and disorientated	0	1	2	3	4

B. CONCERN ABOUT MEDICAL TREATMENT

Clinical management of epilepsy

I am concerned that, for this person, it is difficult……

11	For clinicians to prioritise the treatment of concurrent conditions	0	1	2	3	4
12	To find the right combination of drugs for epilepsy	0	1	2	3	4
13	To differentiate between the effects of learning disability and drug effects	0	1	2	3	4
14	The person has to take medication every day	0	1	2	3	4
15	It is difficult for this persons carers to record seizure activity	0	1	2	3	4
16	Staff and family carers give different information about Seizure activity	0	1	2	3	4

Medication side-effects

17 The person is at a greater risk of side effects because of their ID 0 1 2 3 4

I am concerned that, in this person, medication causes…

18 General malaise 0 1 2 3 4

19 Mood Swings 0 1 2 3 4

C. CARING FOR A PERSON WITH EPILEPSY

I am concerned about this person’s epilepsy because…

20 Family carers lose their independence 0 1 2 3 4

21 Carers are reluctant to ‘let go’ 0 1 2 3 4

22 Carers worry about the person having a seizure when out 0 1 2 3 4

I am concerned that it is hard when caring for this person…

23 For the carers to get anyone to care for the person while he/she is out 0 1 2 3 4

24 For the carers to balance anxiety about risk with the persons choice 0 1 2 3 4

25 To balance personal safety with ‘homeliness’ in the home 0 1 2 3 4

I am concerned for this person because staff/ carers…

26 Cannot tell when they are going to have a seizure 0 1 2 3 4

27 Cannot give the same level of care as the family 0 1 2 3 4

D. SOCIAL IMPACT OF EPILEPSY

Living in the community with epilepsy

I am concerned for this person because…						
28	Epilepsy affects what other people think about their ability	0	1	2	3	4
29	They are not accepted by the community because they have epilepsy	0	1	2	3	4
30	They are isolated because of epilepsy	0	1	2	3	4

Daily Living

I am concerned that because of seizures, the person…						
31	Is less independent	0	1	2	3	4
32	Is not able to work	0	1	2	3	4
33	Is not allowed to decide on his/her own level of risk	0	1	2	3	4
34	Has no privacy even when bathing	0	1	2	3	4
35	It is dangerous for the person to cross the road	0	1	2	3	4

Thank you very much for taking your time

to complete this questionnaire

Corp, A, Curtice, L, Espie, CA , Foley, J, Mantala, K, and Watkins, J (2006) *The Glasgow Epilepsy Outcome Scale for People with Learning Disabilities - Client version (GEOS-Client): a new self-report scale for concerns about having epilepsy.* Journal of Intellectual Disability Research, 50. pp. 161-171.

Glasgow Epilepsy Outcome Scale-
Client Version

(GEOS-C)

Name of person with epilepsy ……………………………………………

Outcome scale competed with ……………………………………………

Relationship to person ……………………………………………

Date of completion ……………………………………………

The following is a list of concerns that have been mentioned by people who have Epilepsy and a Learning Disability. The scale is trying to find out whether the person you care for has any concerns about their epilepsy. We would like you to help the person that you care for fill in the scale. It may help to give examples to explain some issues more clearly.

If the person feels that the concern applies to them, tick the YES box, if the person does not feel it a concern tick the NO box.

During completion:

- The word ‘seizure’ has been used, but can be replaced with a description the person regularly uses.
- Keep the person thinking about only things caused by their epilepsy.
- Remember to focus on the concerns **THEY** have rather than your own concerns about their epilepsy.
- Even if you do not feel their response is correct tick the box according to their answer, the scale is measuring how **THEY** feel about their epilepsy.

Concerns about having seizure - Being afraid of crowded places in case I have a seizure - Not knowing a seizure is going to happen - You could die during a seizure if you live on your own - A seizure can happen anywhere - Not getting any warning - Waiting for the next seizure to happen	**Yes**	**No**
During a seizure - Going in and out of seizures - Having to stay in because I keep having seizures - Having a seizure feels bad - Not knowing what is happening to me - Getting things taken from me if I have a seizure in the street - Wetting myself during a seizure		
After having a seizure - Being tired and sleepy afterwards - Getting confused after a seizure - Not remembering what happened during a seizure - Being scared to go out after having a seizure - Being unsteady and off balance after a seizure - Feeling upset and depressed after a seizure - Having headaches after a seizure		

Concerns about medication - Having to take lots of medication - Doctors changing your tablets - Remembering to take the tablets at the right time - Tablets making me dizzy		
Concerns about what other people think - People think that I am acting it - Feeling embarrassed if I have a seizure while I am out - People calling me names when I have a seizure - People do not know what epilepsy is like - Not being treated like a normal person because of my epilepsy - People sending me to hospital when there is no need - People think that I am staring at them and get angry with me		
Concerns about daily life - Not being able to do as much because of my epilepsy - Not being able to live in my own house because of my epilepsy - Not being able to do my own house work (e.g. cooking or ironing) - Always having to be with someone - Not being able to get a job because of my epilepsy - Seizures stop me learning - Not being able to travel on my own		
Concerns about injury - Hurting myself during a seizure - Having to have stitches - Falling down the stairs when I have a seizure - Getting burnt when I have a seizure - Biting/chewing my tongue during a seizure.		

Thank you very much for taking your time

to complete this questionnaire

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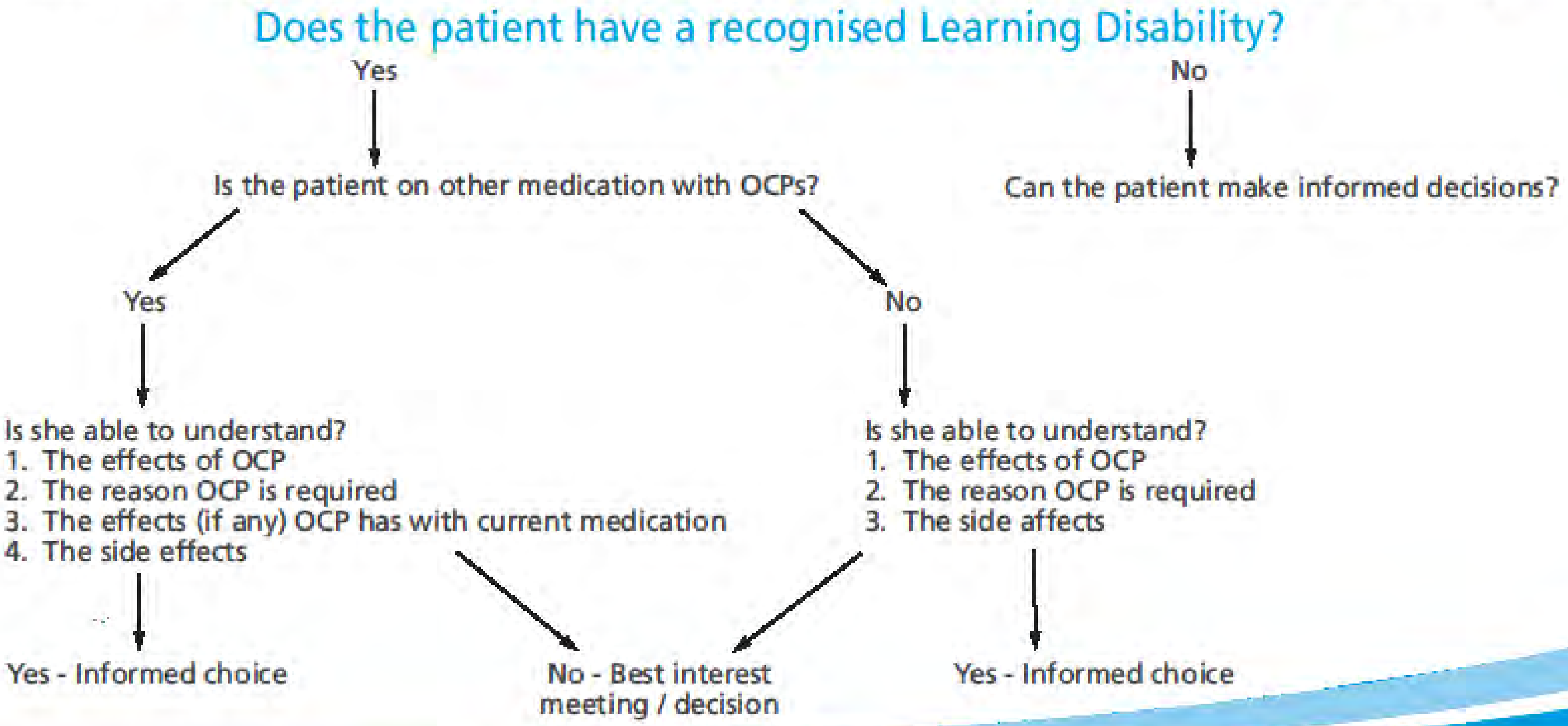
Consenting Learning Disability Patients - Oral Contraceptive Pills (OCPs)



Does the patient have a recognised Learning Disability?

Yes

Is the patient on other medication with OCPs?

Yes

Is she able to understand?
1. The effects of OCP
2. The reason OCP is required
3. The effects (if any) OCP has with current medication
4. The side effects

Yes - Informed choice

No

Is she able to understand?
1. The effects of OCP
2. The reason OCP is required
3. The side affects

Yes - Informed choice

No - Best interest meeting / decision

No

Can the patient make informed decisions?

February 2013 (Review 2016)
Created by Meriel Bradley and Rohit Shankar
Cornwall Partnership NHS Foundation Trust
Head Office, Fairview House, Corporation Road, Bodmin, PL31 1FB

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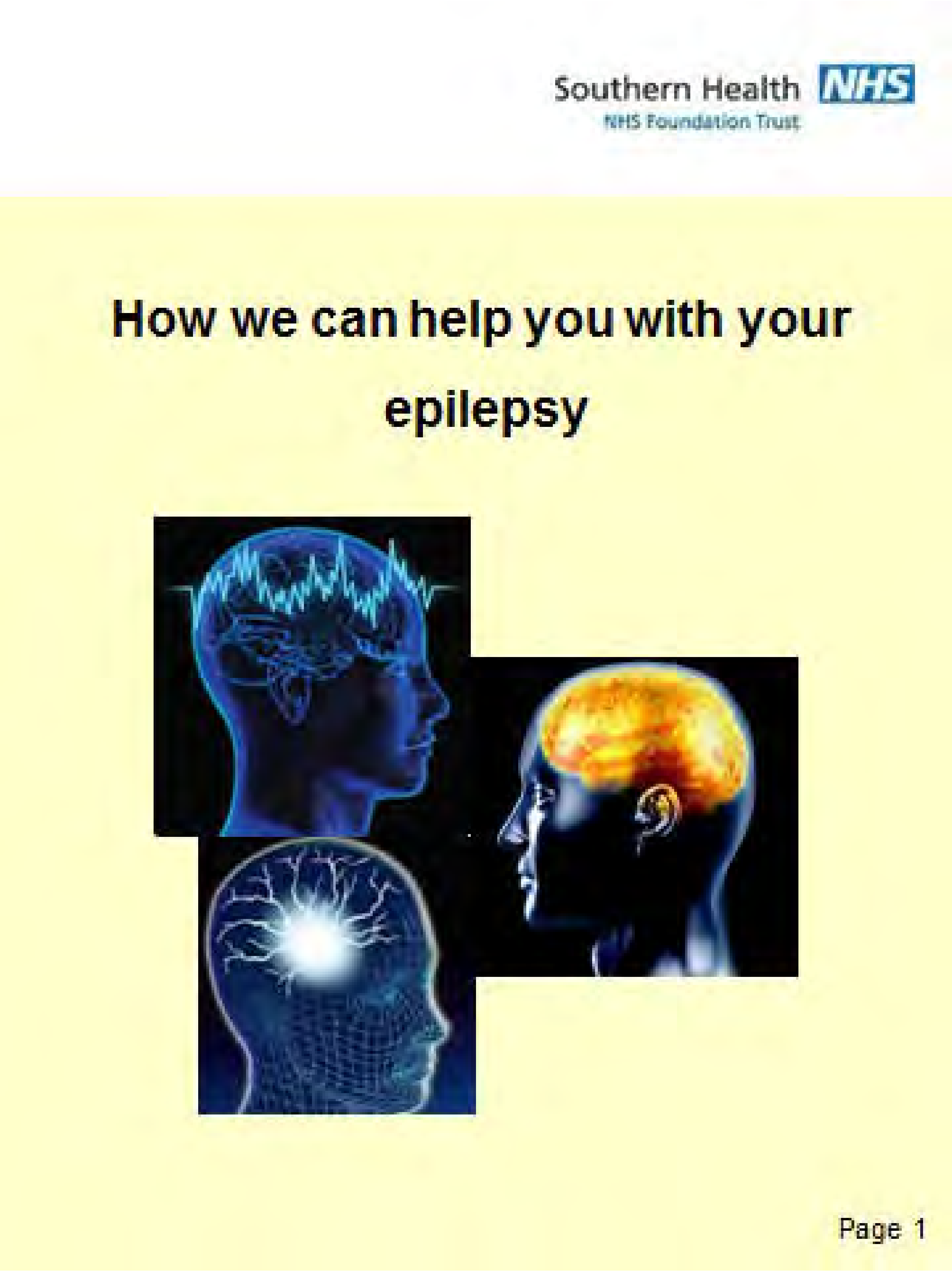
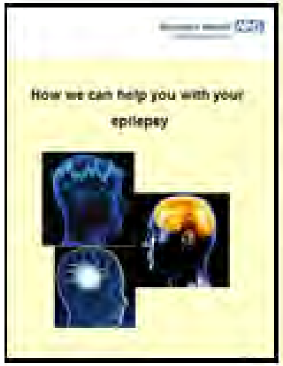
Easy Read Guide to Epilepsy



Southern Health NHS
NHS Foundation Trust

How we can help you with your epilepsy

Page 1



How we can help you with your epilepsy

What is this booklet about?

This booklet is about how **the health team can help people who have epilepsy.**

Epilepsy affects your brain. It can cause a seizure. Some people call the seizure an attack or fit.

Your epilepsy might be managed by your GP, your Neurologist, who is the epilepsy Doctor or the Learning Disability team.

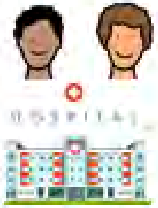
If your epilepsy is managed by the Learning Disability Team, this booklet tells you about the **service user journey** through the **epilepsy map.**

Everyone has a different journey through the map.

This is because **everyone is different** and needs **different help** to get better.

What will happen?

A person from the health team might come to **visit you at home**.



If you are in hospital, the team of people who work there will come **and talk to you**.

On your journey, we will talk to you about how you are doing.

1

There are lots of parts of the journey.

At the beginning, the health team need to know more about you and your epilepsy.

Southern Health NHS
NHS Foundation Trust

The health team will:

- **Talk to you** about how you are and **what help you want** from the health team.

- **Talk to people** that know you well to find out about your epilepsy and what it has been like.

- We will ask you about **any treatment** that you have had and if you take any medication for your epilepsy.

- **Find out information** from the notes in your file.

2

The next part of the journey is called the **assessment**.

This means understanding how your epilepsy affects you.

Southern Health NHS
NHS Foundation Trust

The health team will:

- **Talk to you** about how your epilepsy is now, and any problems you may have with it.

- They will ask you how long your seizure, attack or fit lasts and how they affect you.

- Collect **information from different people**. This might be from your GP, your Neurologist, who is the epilepsy Doctor or someone else.

- Ask you how your epilepsy affects you every day. This is so we can help you to keep safe.

3

The next part of the journey is called the **formulation**.

This is how we decide what to do next.

The health team will:

- Look at all the information they have about you and your epilepsy.

- They will have a meeting to discuss how best to support you and help you manage your epilepsy.

- They will talk to you and your carers about this.

4

The next part of the journey is called **management.** This is how we work with you to keep you healthy and safe.

The health team will:

- Use all the information to **make a plan**. This is called an **epilepsy care plan**.
- This care plan will include **lots of advice** from your health team.

- This plan will **have lots of ideas** about how to help you manage your epilepsy to keep you **healthy and safe.**

5

The last part of the journey is called the **review**.

This is how we check to see what is working and if anything needs to change.

The health team will:

- **Check that what they have said is working.**

- Check that everyone understands your epilepsy care plan.

- If the care plan is **not** working, the **health team will work with everyone to make it better.**

Your epilepsy care plan should be **reviewed once a year**. This may be by the health team, your GP or your Neurologist.

This **booklet is about the service user journey** on the **Epilepsy Map**.

It was made by Southern Health NHS Foundation Trust, August 2016.

We would like to thank all service users who have epilepsy who helped to make this booklet.

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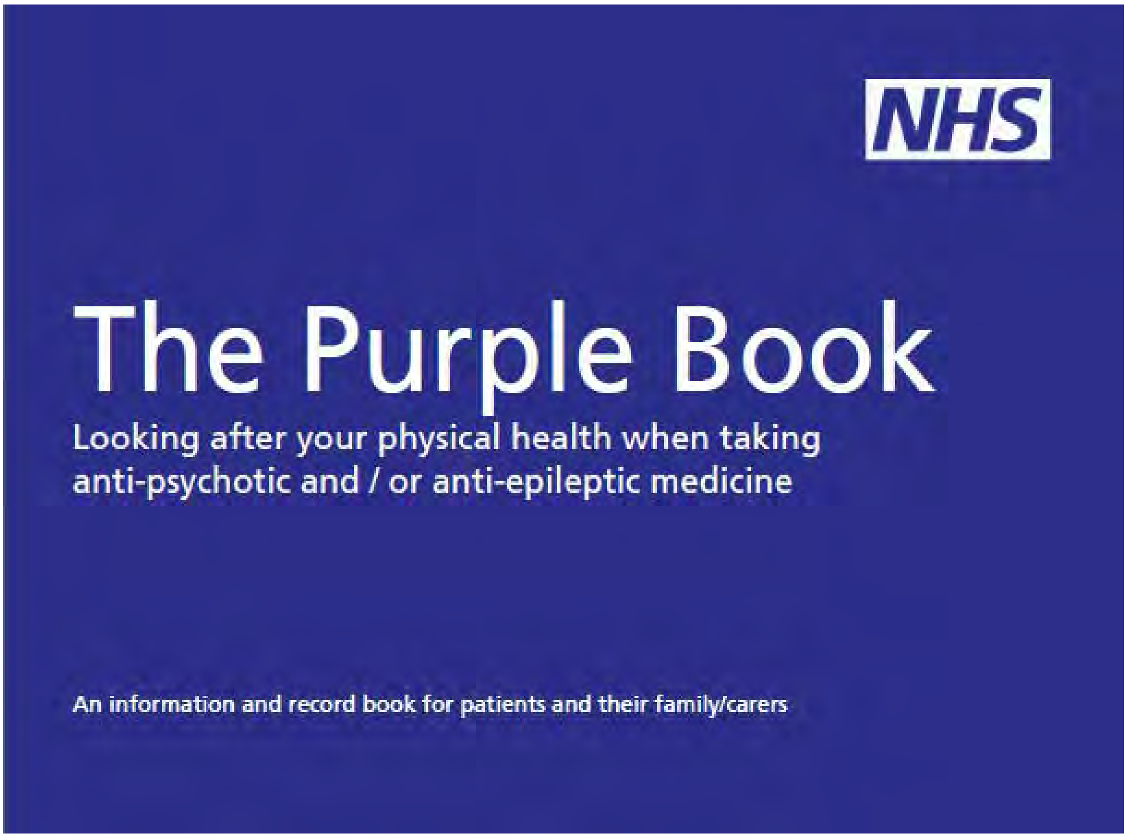


NHS

The Purple Book

Looking after your physical health when taking
anti-psychotic and / or anti-epileptic medicine

An information and record book for patients and their family/carers

The Purple Book was developed as an information and record book for patients, their families and their carers.

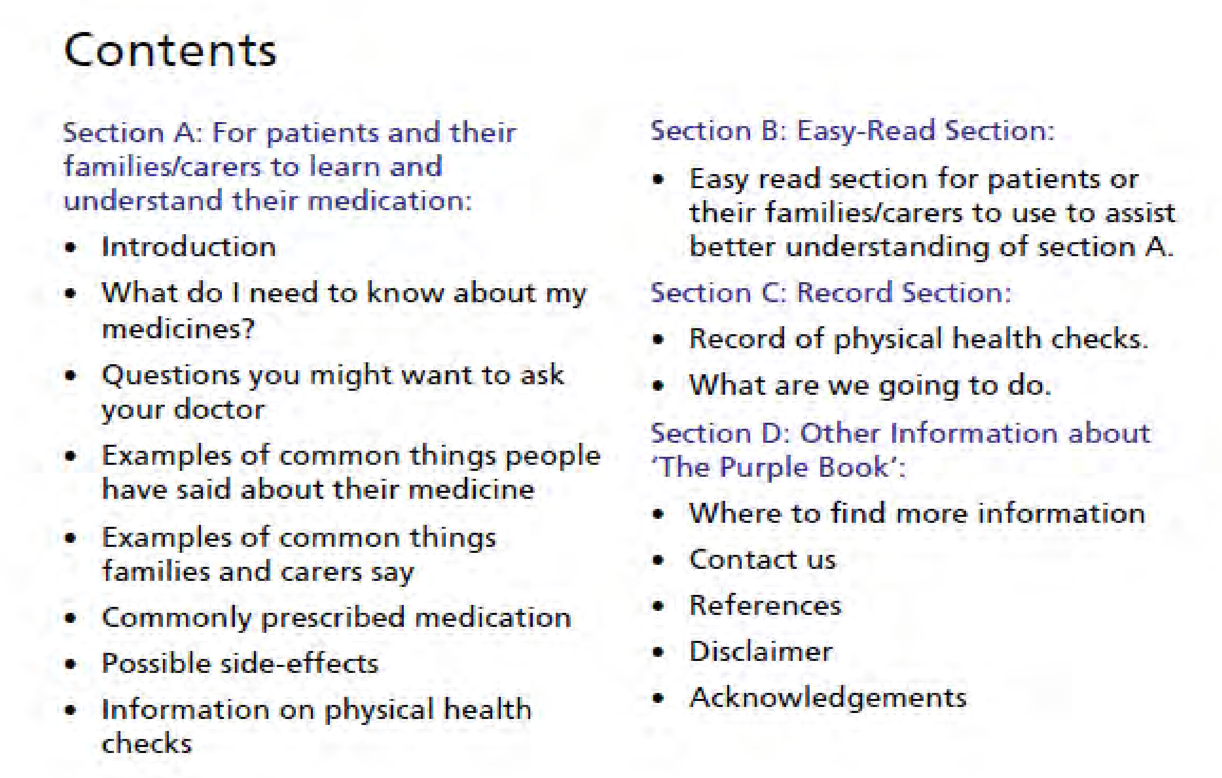
On the next page you will find some information as to what is in the book.

The full PDF copy of the booklet can be requested from

Mrs Sarah Mitchell

sarah.mitchell20@nhs.net

Phone - 01872221551



Contents

Introduction

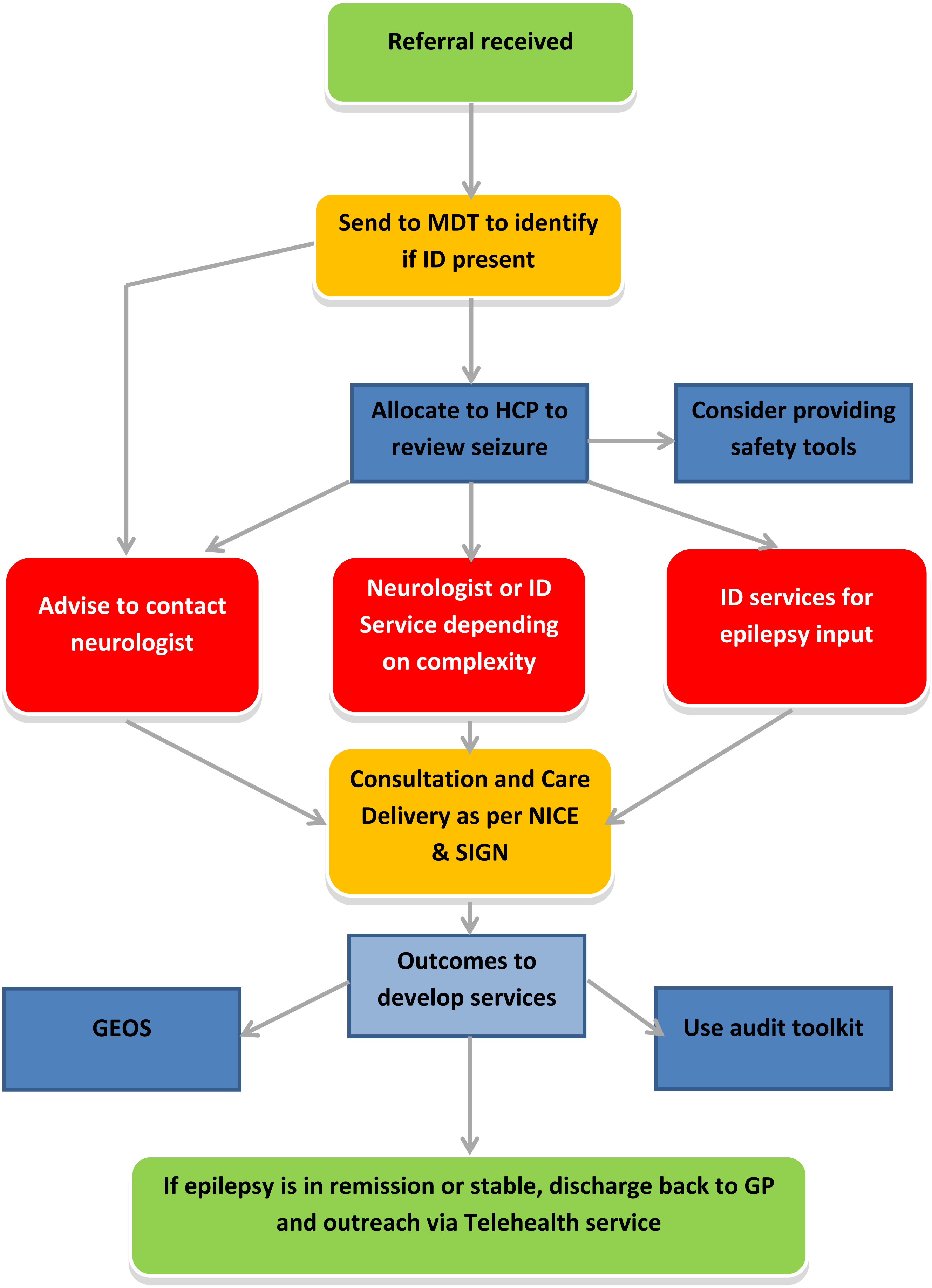
This booklet will help you or your family/carers

- Understand what you need to know and how to ask for information.
- Be aware of side effects and what you can do.
- Record any test results and changes in your health.
- Monitor your health.
- Find more information about your illness or medication.

What should I do with this booklet?

- Read the information.
- Use the section at the back to keep a record of your health checks, so you can be involved in looking after yourself.
- Take it with you each time you see a doctor or other member of the team about your health.

Pathway for Epilepsy in ID



Referral received

Send to MDT to identify if ID present

Allocate to HCP to review seizure

Consider providing safety tools

Advise to contact neurologist

Neurologist or ID Service depending on complexity

ID services for epilepsy input

Consultation and Care Delivery as per NICE & SIGN

Outcomes to develop services

GEOS

Use audit toolkit

If epilepsy is in remission or stable, discharge back to GP and outreach via Telehealth service

Frequently asked questions

Can over-the-counter medication affect my epilepsy?

Some medicines that you pick up off the shelf at the drug store can potentially increase the frequency of seizures in people with epilepsy, or even cause seizures for the first time.
www.epilepsy.com/learn/triggers-seizures/over-counter-medications

Can flashing lights cause epilepsy?

Some flashing of lights can cause epilepsy. This type of epilepsy is called photosensitive epilepsy. It is a type of epilepsy in which all, or almost all, seizures are triggered by flashing or flickering light. Both natural and artificial light may trigger seizures. Some patterns, such as stripes or checks, can also trigger seizures in some people with photosensitive epilepsy.
www.epilepsy.org.uk/info/photosensitive-epilepsy

Does the condition of musicogenic epilepsy exist?

Musicogenic epilepsy, which is a form of reflex epilepsy, is characterised by epileptic seizures which are triggered by specific music experiences. Individuals with musicogenic epilepsy differ in the music trigger, but may have similar seizures.

Can medication for mental health conditions affect epilepsy, or vice versa?

Some medication for mental health conditions such as anxiety, depression and psychosis can make epilepsy worse. If you are taking any medication, ask your GP for more information. Stress associated
with the epilepsy may also cause mental health problems.
http://iacapap.org/wp-content/uploads/I.2-EPILEPSY-072012.pdf

Can epilepsy cause challenging behaviours?

Challenging behaviours can be more common in people with some types of epilepsy, i.e. frontal or temporal lobe seizure. Also, chemical imbalance as a result of taking anti-epileptic drugs may sometimes affect behaviour.
www.epilepsydiagnosis.org/index.html

Can epilepsy cause mental illness?

There is no direct association, but the frequency of mental illnesses and mood or psychotic problems are higher in people with epilepsy than in the general population.
emedicine.medscape.com/article/1186336-overview

Can people with epilepsy drink alcohol?

You may be able to drink in moderation, but only after consulting your doctor or pharmacist because alcohol can make drug side-effects worse. Excessive or heavy drinking is likely to increase the risks of seizures and lead to other health problems.
www.ibe-epilepsy.org/downloads/Alcohol%20and%20Epilepsy.pdf

I had a fit recently. What is the advice on driving?

If you drive a car or a motorbike and have had a fit, you should tell the Driver and Vehicle Licensing Agency (DVLA) immediately. You can either do this online, or fill in form FEP1 and send it by post to the DVLA. If you cannot do this on your own, you should ask your carer or social care manager to help you. Until you hear from the DVLA you must not drive.

Your licence may be taken away if you are considered not safe to drive because of your epilepsy. However, you can reapply for your driving licence if your epilepsy improves and you are considered safe to drive again. You must follow your doctor's advice about your treatment and check-ups for epilepsy, and the DVLA must be satisfied that as a driver you are not likely to be a source of danger to the public. Please visit this website for more details: www.gov.uk/epilepsy-and-driving

You can also contact Epilepsy Action, New Anstey House, Gate Way Drive, Leeds, LS19 7XY, Freephone: 0808 800 5050; or the Epilepsy Society, Chalfont St. Peter, Gerrard Cross, Bucks SL9 0RJ, Tel: 01494 601300.

I am on anti-epileptic medication and am planning to have a baby. What are the risks to me and my child?

Most women with epilepsy have healthy pregnancies and give birth to a healthy baby. You should talk to your doctor or nurse if you are planning to become pregnant. This is because your epilepsy and epilepsy medicines might slightly increase your risk of having a baby with a birth problem. You can also get more information from the following website: www.nhs.uk/Conditions/Epilepsy/Pages/living-with.aspx

Can my epilepsy medication affect my birth control?

Some medications used for epilepsy can reduce the effectiveness of some types of contraception. These include the combined oral contraceptive pill – often known as 'the Pill' – and the progesterone-only pill (POP) or 'mini pill'. Epilepsy medication can also reduce the effects of contraceptive injections, patches and implants. Some contraceptives can also reduce the effect of epilepsy medication. Ask your GP or epilepsy specialist for advice. You can also get more information at: www.nhs.uk/Conditions/Epilepsy/Pages/living-with.aspx

Acknowledgements

This appendix of tools for people with Epilepsy and an ID was compiled by;

R. Shankar and S. Mitchell

with the help of valuable contributions from

- 1. Cornwall Partnership NHS Foundation Trust
- 2. Southern Healthcare Trust
- 3. 2gether NHS Foundation Trust
- SUDEP Action
- Epilepsy Society
- Epilepsy Action

purple light for epilepsy