



Public Health
England

Protecting and improving the nation's health

Making reasonable adjustments to epilepsy services for people with learning disabilities

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

About Improving Health and Lives

Improving Health and Lives (IHaL) was set up in April 2010 to provide high quality data and information about the health and healthcare of people with learning disabilities. The information helps commissioners and providers of health and social care to understand the needs of people with learning disabilities, their families and carers, and, ultimately, to deliver better healthcare.

IHaL is a collaboration between Public Health England (PHE), the Centre for Disability Research at Lancaster University and the National Development Team for Inclusion. Since April 2013, IHaL has been operated by PHE.

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Published November 2014

PHE publications gateway number: 2014472









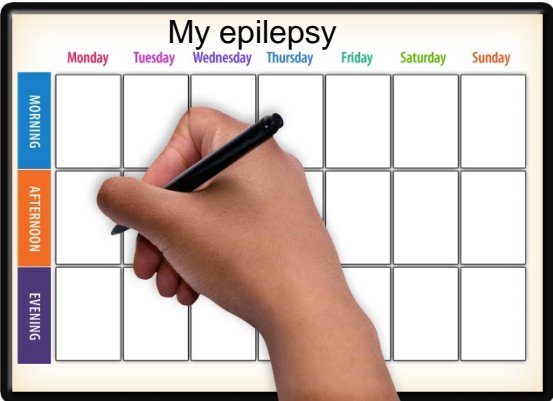
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Note: All weblinks checked October 2014

Easy-read summary

	<p>Epilepsy is an illness that affects the brain.</p> <p>It can cause people to have fits or seizures.</p>
	<p>People with learning disabilities are more likely to have epilepsy than other people.</p>
	<p>It can be difficult for people with learning disabilities and family carers to get the right support with epilepsy.</p>
	<p>If people don't get the right support with their epilepsy then they may need to go to hospital as an emergency.</p> <p>Some people may die because of their epilepsy.</p>

	<p>The law says public services should put 'reasonable adjustments' in place to help people with learning disabilities use them. This means they need to change their services so they are easier to use.</p>
	<p>This report has lots of information about reasonable adjustments in epilepsy services. Professionals and carers can use them to get better services for people with learning disabilities and epilepsy.</p>
	<p>The report also has some examples of how local services have put reasonable adjustments in place so that people with learning disabilities and epilepsy can use epilepsy services.</p>

The pictures in this report are from Photosymbols: www.photosymbols.co.uk



Introduction

Under the Equalities Act 2010,¹ public sector organisations have to make changes in their approach or provision to ensure that services are accessible to disabled people as well as everybody else. IHaL has a database of examples of reasonable adjustments made by health services (www.ihal.org.uk/adjustments/).

This report is the eighth in a series of reports looking at reasonable adjustments in a specific service area (see Appendix A). The aim of these reports is to share information, ideas and good practice in relation to the provision of reasonable adjustments.

We searched for policy and guidelines that relate to people with learning disabilities and epilepsy. A summary of this information is below. We looked at websites to find resources that might be of use to people with learning disabilities and epilepsy or to those supporting them. There is a brief description of these and information about how to obtain them in the resource tables.

We put a request out through the UK Health and Learning Disability Network, a major email network for people interested in services and care for people with learning disabilities. We asked people to send us information about what they have done to improve epilepsy care for people with learning disabilities. Examples of what has proved useful are given at the end of the report.

People with learning disabilities and epilepsy

Evidence and research

Prevalence and mortality

Recent studies looking at the proportion of people with learning disabilities who have epilepsy show a range of rates.²⁻⁷ This is because these studies used different definitions of epilepsy and took different approaches. However, roughly one out of every five people with learning disabilities also has epilepsy.² This is much more common than for other people. In the general population only one person in 100 has epilepsy.⁸ This means that a large proportion of people with epilepsy also have learning disabilities. The recent Confidential Inquiry into premature deaths of people with learning disabilities found that epilepsy was the most common long-term condition for the cohort of people with learning disabilities – 43% of them had been diagnosed with epilepsy.⁹

Epilepsy and convulsions have been identified as a common, possibly preventable, cause of death for people with learning disabilities.¹⁰ There is evidence that epilepsy is associated with increased mortality in people with learning disabilities even taking into account their higher rates of epilepsy.^{3, 11-13} Studies show that people with learning disabilities are at a higher risk of sudden unexpected death in epilepsy (SUDEP).^{11, 13} A small study found SUDEP was the second most common cause of death among adults with epilepsy and learning disabilities.¹¹

Co-occurring health problems

People with learning disabilities and epilepsy are more likely to have other health problems, such as arthritis, gastrointestinal disease and stroke.⁷ Additionally, they have a higher rate of fractures. This is likely to be due to a number of factors – reduced mobility, injuries incurred during seizures and reduced bone density due to drugs, including those used to treat epilepsy.¹⁴ There is mixed evidence about an association between epilepsy and mental health problems in people with learning disabilities. Some studies report no association between mental health problems and epilepsy for adults with learning disabilities.^{7, 15-17} However, a prospective case control study showed adults with learning disabilities and epilepsy had a much higher risk of developing psychiatric disorders over a 12-month period than those without epilepsy.¹⁸

Diagnosis

It is difficult to diagnose and assess epilepsy in people with learning disabilities for a number of reasons. Communication problems mean an increased reliance on the ability of family and paid carers to provide a clinical history. There is evidence that cognitive, behavioural and motor problems and side-effects of medication in people with learning disabilities can be confused with seizure activity.^{19,20} According to NICE guidelines, diagnosis of epilepsy should be by a specialist and EEGs and neuroimaging should be used appropriately as part of investigations.²¹ However, in some areas fewer than half of people with epilepsy and learning disabilities are reported as having EEG investigations and even fewer neuroimaging.²² Some people with severe or profound learning disabilities may struggle to cope with the investigations necessary for diagnosis²³ and in such situations there is a need to make reasonable adjustments so that people with learning disabilities can tolerate the investigations they need. It has been argued that given the potential for misdiagnosis in people with learning disabilities there should be better education of health professionals about this issue in general and the diagnosis should be reviewed annually.¹⁹

Management

Glover and Evison²⁴ looked at hospital admissions for people with learning disabilities that should be avoidable. They found that the main cause for such admissions was convulsions and epilepsy. This accounted for more than 40% of emergency admissions that could be avoided. This high rate of emergency hospital admissions for epilepsy suggests there are also problems with the management of epilepsy for people with learning disabilities. There are clearly significant health service costs as a result of the large number of bed days in hospitals for these epilepsy admissions.

The Confidential Inquiry showed that more people with learning disabilities were given medication for epilepsy compared to the controls.⁹ Despite the high use of medication for people with learning disabilities there is a lack of research evidence about this.²⁵ The National Institute for Health and Care Excellence (NICE) recommends regular structured reviews for people with epilepsy.²¹ People should not be maintained on treatment that is ineffective or poorly tolerated. People with learning disabilities may be more likely to have adverse cognitive effects of anticonvulsant medication. They also might have difficulties in reporting side-effects. Therefore, it is important that clinicians allow sufficient time at appointments to achieve effective management. In the general population, two-thirds of adult respondents reported being offered or attending a treatment review for their epilepsy in the last year.²⁶ The Confidential Inquiry⁹ had concerns that some people labelled as having epilepsy were not receiving regular reviews.

NICE guidance²¹ says that people with learning disabilities should have the same access to treatment as everyone else. This should be undertaken by an epilepsy specialist within a multidisciplinary learning disability team. It has been shown that in secondary care, 54% of adults with epilepsy had inadequate care. The main problems were lack of access to specialist care and inadequate drug management.²⁷ A recent report showed that almost half of acute and foundation trusts surveyed did not offer access to learning disability epilepsy specialist nurses.²⁶ Studies show that fewer people with learning disabilities have well controlled epilepsy.²⁸ The Confidential Inquiry⁹ highlighted concerns that in some cases NICE guidelines were not followed. These cases often related to the management of epilepsy.

Policy and guidance

This section describes some of the policies and guidance available to support people with learning disabilities and epilepsy. People with learning disabilities should be able to access epilepsy services, with appropriate reasonable adjustments. This should ensure that they receive the same quality of treatment as people without learning disabilities.

National service framework for long-term conditions (2005)

This national service framework²⁹ was designed to support a structured approach to the treatment and care of people with long-term conditions, including a focus on neurological conditions. It outlines 11 evidence-based, quality requirements that aim to ensure effective service delivery that will improve the quality of life for those living with long-term conditions. There is a reference to this framework benefitting people with learning disabilities but no specific guidance in relation to this group.

<https://www.gov.uk/government/publications/quality-standards-for-supporting-people-with-long-term-conditions>

NICE clinical guidelines (2012)

The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care

Clinical guidance on the diagnosis and management of epilepsy²¹ was most recently updated in 2012. This gives evidence-based advice on the care and treatment of children, young adults and adults with epilepsy. There is a recommendation that people with complex epilepsy should be managed by multidisciplinary teams that include neurologists. There is guidance on the diagnosis, investigations and management of epilepsy in people with learning disabilities. The report acknowledges that people with learning disabilities have traditionally received suboptimal care and less access to

specialist epilepsy services. There is no explicit mention of reasonable adjustments for disabled people in this guidance.

<http://www.nice.org.uk/guidance/CG137/guidance>

Clinical commissioning policy: Vagal nerve stimulation for epilepsy (2012)

Most people with epilepsy are able to have this controlled with anti-epileptic drugs. For those who are not, surgery or vagal nerve stimulation (VNS) may be treatment options. Having a learning disability does not rule out surgery for epilepsy. This guidance is explicit that VNS should be available to those who meet the criteria even if they have a learning disability.³⁰

www.england.nhs.uk/wp-content/uploads/2013/08/d04-p-d.pdf

National indicators

The NHS Outcomes Framework 2014/15³¹ includes a domain about enhancing the quality of life for people with long-term conditions. It includes a specific indicator (2.3ii) on reducing unplanned hospitalisation for epilepsy in people aged under 19. Indicator 1.7 addresses reducing premature death of people with learning disabilities. This is relevant because many deaths related to epilepsy may be avoidable.¹⁰

General medical services contract 2014/15

Guidance and audit requirements

This guidance³² provides information on changes to the general medical services (GMS) contract for 2014/15. The learning disabilities health check scheme is being continued. This should include a collaborative review with the patient and carer about the person's epilepsy.

<http://bma.org.uk/>

[/media/files/pdfs/practical%20advice%20at%20work/contracts/gps/gms_contract2014-2015_guidance_audit_requirements.pdf](http://bma.org.uk/media/files/pdfs/practical%20advice%20at%20work/contracts/gps/gms_contract2014-2015_guidance_audit_requirements.pdf)

2014/15 General medical services contract quality and outcomes framework guidance for GMS contract 2014/15

The quality and outcomes framework³³ (QOF) is an incentive scheme to reward GP practices in relation to their care for patients. Participation in the QOF is voluntary but there are financial rewards for practices scoring highly on the indicators. Changes to the QOF are agreed as part of wider changes to the GMS contract. In relation to epilepsy care, two QOF indicators have been retired in 2014/15 but there is still an indicator (EP001) that states "the contractor establishes and maintains a register of patients aged 18 or over receiving drug treatment for epilepsy."

<http://bma.org.uk/-/media/files/pdfs/practical%20advice%20at%20work/contracts/gpqofguidance2014-15.pdf>

Other reports

Report by the All-Party Parliamentary Group (APPG) on Epilepsy: Wasted money, wasted lives (2007)

This report²⁸ said that NHS epilepsy services are inadequate and highlighted how money is wasted on services. It concluded that it is possible to deliver improved services while cutting costs.

It acknowledged that people with learning disabilities are more likely to have epilepsy and that there is a greater risk of this being difficult to control. It said that people with learning disabilities are not well served by epilepsy services. The APPG recommended increasing numbers of learning disability specialists and epilepsy specialist nurses. It also highlighted the need for guidelines to ensure people with learning disabilities are treated in accordance with NICE guidance.

http://www.gravesendepilepsynetwork.com/PDF/wasted_money_wasted_lives.pdf

Epilepsy12 national report (2012)

This is the first UK-wide national audit of epilepsy care for children and young people.³⁴ It systematically measured the quality of care using 12 performance indicators derived from the NICE and Scottish Intercollegiate Guidelines Network (SIGN) epilepsy guidance. It concluded that many areas of service delivery could be improved and made recommendations to improve the quality of care that services deliver. None of the recommendations were specific to children and young people with learning disabilities. The audit showed that 35% of the respondents to the patient reported experience measure (PREM) component of the audit had learning difficulties/developmental delay. However, the overall PREM response rate was low. This meant it was not possible to make comparisons between different groups of respondents.

<http://www.hqip.org.uk/assets/NCAPOP-Library/NCAPOP-2012-13/Epilepsy12-Full-National-Report-pub-2012.pdf>

Resources

The four tables that follow list all the information and resources that we have found.

The resources are in four key sections:

- Table 1 lists guidance about the management of epilepsy services and epilepsy. This information is likely to be of use to commissioners, service managers and clinicians
- Table 2 lists resources for professionals/family members and carers. This includes leaflets, factsheets, web-pages and videos. These resources are not easy-read
- Table 3 lists all the easy-read resources we have found. This includes leaflets as well as links to audio information and video. This is where you can find information to use with people with learning disabilities
- Table 4 lists all the relevant free apps we have found. Some of these provide factual data about epilepsy, such as information about types of seizures and up-to-date research evidence. Others are designed for people with epilepsy (or their family members or carers) to use to aid management of their epilepsy. There is one app that can detect a seizure and text this information along with GPS co-ordinates to a designated person

Some resources may be available from more than one site, but we have only given one link for each resource. We have only included resources that are free to download, although some of the websites also include resources you can buy.

Table 1: Guidance about the management of epilepsy services and epilepsy

Theme	Description	Provider	Link
Guidance about epilepsy services			
A critical time for epilepsy in England (2013)	This report is aimed at clinicians, health service commissioners and elected officials.	Epilepsy Action	www.epilepsy.org.uk/sites/epilepsy/files/campaigns/ACT/Epilepsy%20Action%20-%20A%20Critical%20Time%20%282013%29.pdf
Report by the All-Party Parliamentary Group on Epilepsy: Wasted money wasted lives (2007)	All-Party Parliamentary Group report on the human and economic cost of epilepsy.	All-Party Parliamentary Group on Epilepsy	http://www.gravesendepilepsynetwork.com/PDF/wasted_money_wasted_lives.pdf
Improving	Department of	Department of	http://webarchive.nationalarchives.

Services for people with epilepsy (2003)	Health Action Plan in response to the National Clinical Audit of Epilepsy-Related Death	Health	gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4010537
Better value, better care – your guide to commissioning in epilepsy	This booklet provides information for health commissioners about how to consider the needs of epilepsy patients by commissioning epilepsy care.	Epilepsy Action	www.epilepsy.org.uk/sites/epilepsy/files/primary-care-resource/epilepsyaction-primary-care-commissioning-book.pdf
Epilepsy: A resource for primary care	A website resource to help GPs implement services for epilepsy patients in line with recently updated national guidance and the QOF. It includes tools and templates.	Epilepsy Action	www.epilepsy.org.uk/professionals/healthcare/primary-care-resource-pack
Guidance about the management of epilepsy			
The Epilepsies: The diagnosis and management of the epilepsies in adults and children in primary and secondary care (2012)	Clinical guidelines about the treatment and care of people with epilepsy in the NHS in England and Wales.	National Institute for Health and Care Excellence (NICE)	www.nice.org.uk/nicemedia/live/13635/57784/57784.pdf
Clinical commissioning policy: Vagal nerve stimulation for epilepsy (2012)	This document outlines the criteria under which Vagal Nerve Stimulation is commissioned by the NHS Commissioning Board.	NHS Commissioning Board	www.england.nhs.uk/wp-content/uploads/2013/08/d04-p-d.pdf
National statement of good practice for the	This National Statement of Good Practice provides a series of	Joint Epilepsy Council Good Practice Initiative	www.leedsmet.ac.uk/hss/docs/nat_statement.pdf

treatment and care of people who have epilepsy (2002)	recommendations for attaining high quality NHS treatment and care for people with epilepsy in England.		
Managing epilepsy in primary care	Articles about epilepsy designed for professionals. These are based on research evidence and UK and European guidelines and may contain technical language.	Patient.co.uk	www.patient.co.uk/doctor/managing-epilepsy-in-primary-care

Table 2: Resources for professionals/family members and carers

Theme	Description	Provider	Link
General information about epilepsy			
All about epilepsy - part 1: The facts about epilepsy	Film about epilepsy: what it is, diagnosis, seizures and treatment. (Approx 20 minutes). Available in different languages.	Epilepsy Society	www.youtube.com/watch?v=Qu7Xaai02b0&list=PLUpmOw0NN8nUzbKTGx7EUkkkFSuhqwO-7&index=2
Everything you need to know about epilepsy – a resource for parents	A series of 25 factsheets with information for any parent whose child has been diagnosed with epilepsy.	Epilepsy Scotland	www.epilepsyscotland.org.uk/parents/info_235.html
Living with epilepsy	A series of online leaflets aimed at patients. They are not easy read so may be more use for carers.	Patient.co.uk	www.patient.co.uk/health/living-with-epilepsy
Information leaflets about epilepsy	A range of information leaflets for professionals, family and carers. There are 18 in total covering the following topics: epilepsy and seizures;	Epilepsy Research UK	www.epilepsyresearch.org.uk/about-epilepsy/information-leaflets/information-downloads/

	treatments; risk and safety.		
What is epilepsy?	Web pages with information for professionals, family and carers about epilepsy. There are links to further information about causes, diagnosis and treatment. There are also links to a range of videos.	Epilepsy Research UK	http://www.epilepsyresearch.org.uk/about-epilepsy/
Learning disability and epilepsy	Web pages with information for professionals, family and carers about learning disability and epilepsy. There are links to further information about treatment and seizures.	Epilepsy Society	http://www.epilepsysociety.org.uk/learning-disability-and-epilepsy#.VE-pGfl_sII
Learning disabilities and epilepsy	Web pages with information for professionals, family and carers about learning disability and epilepsy. There is information about diagnosis treatment and support.	Epilepsy Action	www.epilepsy.org.uk/info/learning-disabilities
Information about epilepsy	A range of guides about epilepsy that can be downloaded for free.	Epilepsy Scotland	www.epilepsyscotland.org.uk/guides/info_26.html
Types of seizure	Leaflet with information and pictures about different types of seizures	South Staffordshire and Shropshire Healthcare NHS foundation trust.	www.easyhealth.org.uk/sites/default/files/types_of_seizure_0.pdf
More information about epilepsy and seizures	A range of fact sheets about epilepsy that can be downloaded for free.	Epilepsy Scotland	www.epilepsyscotland.org.uk/epilepsy-explained/info_229.html
The experience of living with epilepsy			
All about epilepsy - part 2: people's	Film about the experiences of people with epilepsy	Epilepsy Society	www.youtube.com/watch?v=odrWpUQRcdU&list=PLUpmOw0NN8nUzbKTGx7EUkkkFSuhqWO-

experiences of epilepsy	(including the experience of a mother whose son has epilepsy). (Approx 17 minutes)		7&index=3
Living with epilepsy: Personal stories of people affected by epilepsy	Written stories and video about people's experiences of living with epilepsy.	Epilepsy Scotland	www.epilepsyscotland.org.uk/living-with-epilepsy/info_30.html
Epilepsy diaries			
Seizure diary	A seizure diary to record details of seizures.	Epilepsy Action	www.epilepsy.org.uk/sites/epilepsy/files/files/epilepsy-action-seizure-diary-a4.pdf
Epilepsy diary	A seizure diary to help people to record information about their epilepsy.	Epilepsy Scotland	www.epilepsyscotland.org.uk/pdf/Seizure_diary_-_final.pdf

Table 3: Easy-read resources

Theme	Description	Provider	Link
Easy read resources about epilepsy			
Epilepsy: Staying safe	Information leaflet for carers - Sudden Unexpected Death in Epilepsy (SUDEP) (8 pages)	Leicestershire Partnership NHS Trust	www.ldhealthnetwork.org.uk/docs/sudepc.pdf
Learning about epilepsy – an easy English booklet	An information booklet about epilepsy (40 pages).	Epilepsy Foundation (Australian organisation)	www.epinet.org.au/downloads/File/Learning%20about%20Epilepsy%20Easy%20English_WEB%2015_05_13.pdf
Learning about epilepsy – an easy English booklet	An audio version of the information booklet about epilepsy (approx. 12 minutes).	Epilepsy Foundation (Australian organisation)	www.epinet.org.au/downloads/File/Learning_about_Epilepsy%20audio%20complete.mp3
What is epilepsy?	Information leaflet about epilepsy (11 pages).	South Staffordshire and Shropshire Healthcare NHS foundation trust.	www.easyhealth.org.uk/sites/default/files/what_is_epilepsy_0.pdf
Epilepsy	Information leaflet about epilepsy (22 pages).	The Elfrida Society	www.easyhealth.org.uk/sites/default/files/epilepsy_0.pdf

Epilepsy	Information leaflet about epilepsy (11 pages).	Easyhealth	www.easyhealth.org.uk/sites/default/files/null/Epilepsy.pdf
Epilepsy	Information leaflet about epilepsy (25 pages).	The Foundation for People with Learning Difficulties, Prodigy and Easyhealth	www.easyhealth.org.uk/sites/default/files/Epilepsy%20-%20EH.pdf
Epilepsy	Online pages with information about epilepsy.	NHS Inform	www.nhsinform.co.uk/Easy-Info/HealthConditions/Epilepsy
Understanding epilepsy	An online booklet with audio.	BTM	www.btm.org.uk/easy-read
Living with epilepsy	An information leaflet about living with epilepsy (12 pages).	Epilepsy Scotland	www.epilepsyscotland.org.uk/pdf/LivingWithEpilepsy.pdf
Epilepsy Liaison Service	An information leaflet about the epilepsy liaison service – what they do and how to contact them (11 pages).	Sheffield Teaching Hospitals NHS Foundation Trust	https://www.signpostsheffield.org.uk/dms/sign/management/corporate-communications/documents/Epilepsy-Liaison-Service--PDF--179KB-.pdf
Alcohol and epilepsy	Information leaflet about alcohol with a section about alcohol and epilepsy.	Easyhealth	www.easyhealth.org.uk/sites/default/files/null/alcohol%20and%20epilepsy.pdf
Investigations for epilepsy			
Having an EEG	This leaflet explains what happens when you go to hospital for an EEG (8 pages).	The Elfrida Society	www.easyhealth.org.uk/sites/default/files/null/having_an_eeg_2.pdf
Having an EEG	This leaflet explains about having an EEG (8 pages).	Shropshire County Primary Care Trust	www.easyhealth.org.uk/sites/default/files/null/having_an_eeg.pdf
Having an EEG	This leaflet explains about having an EEG (2 pages).	Dorset County Hospital NHS Foundation Trust	www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=28
What happens during an EEG test?	Film about going for an EEG. (Approx. 1 minute)	Epilepsy Society	https://www.youtube.com/watch?v=KXS268XsRic
Having a CT scan	This leaflet explains what happens when you go to hospital	The Elfrida Society	www.easyhealth.org.uk/sites/default/files/having_a_ct_scan.pdf

	for a CT scan (8 pages).		
Going for a CT scan	This leaflet explains what happens when you go to hospital for a CT scan (4 pages).	South Staffordshire and Shropshire Healthcare NHS foundation trust.	www.easyhealth.org.uk/sites/default/files/going_for_a_ct_scan.pdf
Having a CT scan	An information leaflet about having a CT scan (3 pages).	Health Awareness Group Devon	www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/acute-hospitals/treatments-procedures/Having-a-CT-scan-word.doc
Having a CT scan	An information leaflet about having a CT scan (12 pages).	Calderdale and Huddersfield NHS Foundation Trust	www.improvinghealthandlives.org.uk/adjustments/?adjustment=171
Having an MRI scan	This leaflet explains what happens when you go to hospital for an MRI scan (8 pages).	The Elfrida Society	www.easyhealth.org.uk/sites/default/files/having_an_mri_scan.pdf
MRI scan	An information leaflet about having an MRI scan (3 pages) and a page of information for professionals.	Easyhealth	www.easyhealth.org.uk/sites/default/files/MRIscan.pdf
Having an MRI scan	An information leaflet about having an MRI scan (16 pages).	Calderdale and Huddersfield NHS Foundation Trust	www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=172
Preparing for an epilepsy review			
My epilepsy medical review appointment	This booklet helps the person prepare for an epilepsy appointment with the help of their supporter.	Epilepsy Foundation (Australian organisation)	www.epinet.org.au/downloads/File/Epilepsy%20review%20appointment%20Easy%20English%2008_05_13.pdf
Medication for epilepsy			
Lamotrigine (Lamictal) for epilepsy	A leaflet about lamotrigine (12 pages).	South Staffordshire and Shropshire Healthcare NHS foundation trust.	www.apps.sshis.nhs.uk/pils-leaflet-viewer/GetLeaflet.aspx?LeafletId=738

Table 4: Apps related to epilepsy

Theme	Description	Provider	Link
Apps giving information about epilepsy			
Epilepsy UptoDate	This app contains recent information about epilepsy research, diagnosis and treatment.	Ioannis Asterios Mavroudis	Android: play.google.com/store/apps/details?id=com.wEpilepsyUptoDate
Epilepsy Vault	This app gives information about seizure types, medications and treatments.	Ellery Leung	Android: play.google.com/store/apps/details?id=com.appmakr.app548909
E-Action Info	This app is designed to educate patients and carers about epilepsy in a fun and informative way.	UCB Pharma SA	Available in Apple i-store. Information: itunes.apple.com/gb/app/e-action-info-your-epilepsy/id616614882?mt=8
Epilepsy News	Provides up-to-date information about epilepsy from reputable sources.	Apptomics LLC	Available in Apple i-store. Information: itunes.apple.com/us/app/epilepsy-news/id583627136?mt=8
Apps to help manage epilepsy			
Epilepsy Society	This app contains features such as medication reminder, medication list and first aid information. There is a medication reminder to trigger an alarm on the phone. There are links to a seizure diary.	Epilepsy Society	Android: play.google.com/store/apps/details?id=com.nse Also available from the Apple i-store. Information: itunes.apple.com/gb/app/epilepsy-guide/id375345255?mt=8
Epilepsy Toolkit	This app contains features such as medication reminder, medication list and first aid information. There is a medication reminder to trigger an alarm on the phone. There are links to a	Epilepsy Society	Available in Apple i-store. Information: itunes.apple.com/gb/app/epilepsy-tool-kit/id504820506?mt=8

	seizure diary.		
My Epilepsy Diary	This app enables recording of real-time details about seizures, medications, side-effects, moods and triggers. Medication reminder available.	Epilepsy.com (US organisation)	Android: play.google.com/store/apps/details?id=com.myepilepsy.diary
My eDiary Australia	This app enables recording of real-time details about seizures, medications, side-effects, moods and triggers. Medication reminder available.	Epilepsy Action (Australia)	Available in Apple i-store. Information: itunes.apple.com/gb/app/my-e-diary-australia/id362460642?mt=8
Epilepsy App	This app can be used for reminders to take medicines and to register information about seizures, medicines and moods etc.	Developed by Adiljan Abdurihim and Andrius Januska	Android: play.google.com/store/apps/details?id=no.hig.stud.bachelor.epilepsyaapp
Epilepsy Action Seizure Diary	This app helps people to record seizures, manage medications and keep track of their epilepsy.	Epilepsy Action	Android: play.google.com/store/apps/details?id=uk.org.epilepsy.epilepsyaction Also available from the Apple i-store. Information: itunes.apple.com/gb/app/epilepsy-action/id600838291?mt=8
Young Epilepsy	This app is aimed at young people with epilepsy or parents/carers of a child with epilepsy. It is multipurpose with an up-to-date information portal, video and diary that helps track and manage seizures and symptoms.	Young Epilepsy	Android: play.google.com/store/apps/details?id=com.wearefloat.youngpilepsy Also available from the Apple i-store. Information: itunes.apple.com/gb/app/young-epilepsy/id564205130?mt=8
Seizure Log	An app to support logs and good records of seizures.	Seizure Tracker LLC	Available in Apple i-store. Information: itunes.apple.com/gb/app/seizure-log/id410716391?mt=8
Seizure Diary	An app to help track	Gavin Harris	Available in Apple i-store.

	seizures, medications and triggers.		Information: itunes.apple.com/us/app/seizure-diary/id402201129?mt=8
Epi and Me	An app providing tools to collect and store data about seizures, treatment and life circumstances which may affect seizures.	Gilles Huberfeld	Available in Apple i-store. Information: itunes.apple.com/gb/app/epi-me/id595691667?mt=8
Epilepsia App	An app to support people to register day and time of seizures, symptoms that follow, remedies that are being taken and an alarm to remember the time to do it.	Soda Virtual	Available in Apple i-store. Information: itunes.apple.com/gb/app/epilepsia-app/id589429873?mt=8
Seizures	An app to help recording of seizures.	Satoru Systems	Available in Apple i-store. Information: itunes.apple.com/gb/app/seizures/id501329691?mt=8
Apps to detect a seizure			
EpDetect	This app monitors the movement of the person carrying the phone. It can detect a seizure and text a carer with a message and GPS co-ordinates.	Robert Dlugosz	Android: play.google.com/store/apps/details?id=com.rd.epdetect

Examples of reasonable adjustments and case studies

Matthew's book

This project, commissioned by the Humber NHS Trust, is centred around Mr Matthew Prosser. Matthew has profound and complex needs. Matthew's parents, Tony and Tricia, planned the project together with Ken Pugh who has collated the material. Together with key professionals, they prepared a multimedia, interactive, iPad-based guide to Matthew and his care needs. The book includes Matthew's epilepsy management plan and two short videos that show some seizure activity.

The book will follow him wherever he goes, including hospital, to ensure that all staff working with him can quickly find out about the essential aspects of his care and what good practice means for him.

The photographs, videos and audio interviews, together with relevant text have been collated using Apple's iBooks Author software. The book, if necessary, could be shared with another person or a service that has an iPad or an Apple computer. There is no limit to how many books like this may be held on an iPad so, conceivably, a hospital ward could have an iPad with books about the needs of many people with complex needs or communication difficulties.

To view screenshots of Matthew's book, please visit

<http://designforcare.wordpress.com/projects/matthews-book-2/>

For further information please contact Ken Pugh: pugh51@me.com

Confidential Inquiry (CI) cases

The CI considered many of the deaths that were related to epilepsy to be premature and identified a number of issues of concern. These included lack of investigations, planning and review, failure to be treated in accordance with NICE guidance and concerns about the quality of rescue medication training for staff. However, cases were also reviewed where good practice and reasonable adjustments were noted (all names have been changed):

Harry's neurologist provided a 'back up appointment' should Harry's transition to adult neurology be delayed. Harry's paediatrician was seeing him until Harry finished school aged 19 years.

There were several cases where consultant psychiatrists and GPs undertook

home visits for people who found attending an appointment very distressing.

Susan had multiple lengthy hospital admissions as a consequence of her epilepsy. Her care co-ordinator arranged a 'best interests' meeting to focus on ways of improving her care pathway to shorten any admissions and request that the hospital make reasonable adjustments to support her family and provide additional staffing for future admissions. Funding for reasonable adjustments was agreed following this meeting and this enabled Susan to be supported by people that she knew. A system was put in place to alert staff of an impending admission and help to minimise any delay in her being transferred from A&E to the most appropriate ward. It was also agreed that family and care staff were able to visit her in hospital whenever they wished and were provided with a car park pass.

Danny was placed in a general nursing home when his care needs increased. The staff lacked experience and had no specific training in care of people with learning disabilities. They were experienced in the care of people with dementia. The nursing home staff were very willing to learn and take advice in order to meet Danny's needs and they were given training in epilepsy management.

Adam was regularly admitted to hospital following seizures and his GP set up an electronic 'major alert' system to inform other GPs and the out-of-hours locums that Adam required immediate response and admission to hospital. Adam was also flagged on the system used in the A&E department to indicate the need for immediate attention and admission to the same ward.

David had dementia and developed epilepsy, with his seizures becoming more frequent as his condition deteriorated. At a 'best interests' meeting it was agreed that David would move to a downstairs room. The move was well managed as some of David's belongings were moved to a ground floor room for him to use initially during the day. In addition, his changing needs were responded to and as his seizure activity increased funding was provided for waking night time support.

Wendy had an adjustment made to her epilepsy rescue medication protocol that enabled her to join in with outings at the day centre.

Russell had an extensive amount of assisted technology and safety equipment through the organisation's assisted technology programme.

Great Ormond Street Hospital

S is a young woman with profound and multiple learning disabilities who had a severe reaction after surgery. Following this her local psychiatrist referred her to Great Ormond Street Hospital where her needs were recognised and after more surgery she improved dramatically. Her transition to the adult service was managed excellently with joint meetings to make certain that all information was transferred and this ensured great continuity of care.

S is now living in a rural area and her care is well managed; she is often seen by the same professionals and this continuity helps with recognising when she can stay in the community and when she needs to go to the emergency department. Her family and provider are currently working with the ambulance service to ensure that phone operators and front line staff are familiar with S's care plan and needs.

Berkshire Healthcare NHS Foundation Trust – The ME (My Epilepsy) Project

This project was funded and supported by the Queen's Nursing Institute with the aim of engaging people with learning disabilities and epilepsy to learn about their epilepsy and to empower them in relation to the healthcare they receive. They used a group approach with ten participants in each group meeting weekly for ten weeks. The groups followed the PEPE programme (an electronic psycho-educational programme about epilepsy for people with learning disabilities). This is a multimedia course with a holistic approach and it was used alongside other teaching methods such as discussions, role-play and video.

Knowledge of the participants was measured before and after the programme; the Epilepsy Rating Scale³⁵ was also used. The outcome showed that there was an increased awareness of risk and that people were putting their learning into practice and consequently sustaining fewer injuries and falls.

As part of the programme, participants were asked to keep a seizure diary to record relevant information. Following the programme there was a request for this to be published. This means it is now available for all people with learning disabilities and epilepsy to use in consultations with medical staff. Information about their medical history and medication is also in this resource.

It was concluded that participation in the group was an effective way of increasing empowerment and of encouraging people with learning disabilities to engage in their healthcare.

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West Sussex Epilepsy Working Group

An audit by the West Sussex Epilepsy Working Group showed that only about half the people with learning disabilities and epilepsy who attended a neurology clinic were bringing good information about their seizure history and current medication. Following this, the group developed some guidelines. As part of this work they produced an easy-read seizure diary. There are two versions of this to allow for differences in the abilities of individuals to complete these themselves.

For further information please contact corinne.nikolova@nhs.net

Abertawe Bro Morgannwg University Health Board

The health board provides a tertiary service for people with learning disabilities and epilepsy, covering all of south, west and east Wales. Initially, people had to travel to Cardiff to attend specialist epilepsy clinics. However, to make clinics more accessible for patients and their carers, the regular clinics in Cardiff were supplemented by clinics in hospitals across Wales. The clinics are both consultant-led and nurse-led. This has the advantage of decreasing the stress of attending an appointment for some people as they are in a familiar environment. Another strategy used to make the service more accessible is a weekly tele-clinic service for people who are too far away or too ill to attend a hospital clinic. These are pre-booked structured phone calls, led by the epilepsy specialist nurse. Additionally, the service arranges home visits where these are needed.

They have devised easy-read (inclusive communication) appointment letters as well as an easy-read leaflet about sudden unexpected death in epilepsy (SUDEP). They have received a lot of positive feedback about these.

In addition to the regular learning disabilities and epilepsy clinics, they also run more specialist clinics:

Vagus nerve stimulation (VNS) clinic: This was established due to concerns that people with learning disabilities find it more difficult to report side-effects of VNS and therefore require closer monitoring. It is run by the epilepsy specialist nurse. As part of this service, she engages with the neurosurgeons when someone with a VNS is scheduled for surgery and works closely with the neuro-surgical team.

Transition clinics: A number of clinics are run, with varied formats. At the Royal Glamorgan Hospital, the transition clinic is attended by Professor Mike Kerr, the epilepsy specialist nurse, a hospital paediatrician, two consultant psychiatrists from each area and two health team managers. They meet the young people twice prior to transition and they all agree (with input from the patient) who will

manage their future care. The health team manager co-ordinates other referrals that are needed.

Pre-conceptual counselling clinics: These are run by the epilepsy specialist nurse. She works with couples from the pre-conceptual stage and helps with planning for emergencies, adjusting medication if appropriate and linking patients with the consultant-led antenatal team, to plan for a hospital birth. After discharge from hospital, she liaises with the health visitors and practice nurses about ongoing monitoring. As part of this service, the epilepsy specialist nurse makes accessible, personalised resources, which may include recording audio versions.

For further information please contact Christine Hanson (epilepsy specialist nurse) at Christine.Hanson@wales.nhs.uk

Eastern Region

M has complex and, so far, intractable epilepsy. His circle and support team have worked hard to ensure that his seizures have as little impact as possible on his quality of life.

M has a big book called “Me and my epilepsy” to record everything that those supporting M need to know about his epilepsy and how he prefers to be supported. This has helped to ensure a very clear flow of information between those supporting him.

An architect got to know M and his needs before helping M design the part of the house that he lives in. As a result, M now has doors that fold back into his bedroom to bring the outside in on days when his epilepsy enforces a day in bed. He also has a bath in the middle of the room and a porthole in the bathroom door to maximise his privacy and dignity while maintaining his safety. There are sofas around where he can lie whilst recovering from a seizure and still be a part of what is going on around him. This has helped to limit his isolation.

Epilepsy Specialist Service, Nottinghamshire

The Epilepsy Specialist Service in Nottinghamshire is an integrated service for adults with epilepsy and learning disability. The service works with local neurology services and provides nurse-led specialist clinics in the acute hospitals. The learning disability and epilepsy trained nurses are non-medical prescribers. The close partnership with neurology services is crucial. It has resulted in good communication and effective collaboration between learning disability services and neurology.

All new referrals to the specialist clinics are assessed holistically by the consultant nurse with expertise in epilepsy and learning disability and a consultant neurologist. A service audit of their new referrals over a 12-month period showed that 58% of new referrals had undiagnosed or untreated health comorbidity. Some of these health needs are addressed by the service (eg sleep problems, vitamin D deficiency, drug side effects). Others they refer on as appropriate (eg stomach ulcer, hypertension, hypothyroidism, lymphedema, mood disorders). Careful specialist assessment has identified patients in whom the epilepsy diagnosis was incorrect and medication had been successfully withdrawn. The team finds that a proactive and comprehensive approach to assessment is beneficial.

The nurses can make home visits for those unable to access a hospital clinic, for example people with challenging behaviour or palliative care needs. On one occasion the consultant nurse and the consultant neurologist did a joint home visit to a family who were not attending clinic appointments. Since then the family have attended clinic appointments.

In addition to the clinics run within the acute hospitals, they also provide other specialist clinics:

A neurology and learning disability psychiatry clinic is run four times a year. This is attended by patients who are being overseen by learning disability psychiatrists. It provides an opportunity for the psychiatrists to get a neurological opinion about patients they are concerned about, for example people with movement disorders or side-effects from medication. These clinics are held in a learning disability service setting. This can be useful for people who cannot tolerate clinics in an acute setting or for people receiving inpatient services in the local assessment and treatment unit.

Transition clinics: The neurologist and the consultant nurse go into local special schools and the transition nurse identifies children with epilepsy who are coming up to transition. They allocate at least an hour to meet with the child and their family and take a comprehensive history. This compares to the short, time-limited first appointment they used to have in the hospital clinic. This did not provide the opportunity to adopt a holistic approach and explore complex needs. When they hold these clinics, the epilepsy team meet the school nurses, physiotherapists, teachers and paediatricians. The team has found it useful to see the child in a familiar environment when they are well. Family carers have reported finding this first appointment very reassuring as it gives them confidence in the adult epilepsy service. Family members are also given contact details for the epilepsy service and the learning disability acute liaison team. Following the meeting a detailed letter and treatment plan is sent and, with agreement, copied to all adult professionals that will be involved with the young person.

The service has a strong focus on epilepsy awareness training. Over the past year, 650 people have been trained, including family carers, paid carers and health professionals. This has improved the quality of reporting and recording seizures and increased referrals to the team.

The service obtained funding from NICE to develop a series of short films with the help of adults with learning disabilities and epilepsy. The aim of the films is to increase understanding and improve access to the service and to specialist investigations such as MRI, EEG, video telemetry, living with epilepsy, and coming in to hospital for vagal nerve stimulation surgery. Photo booklets will accompany the videos that are accessible on the intranet, internet and in hard copies.

For further information please contact Sarah Pashley (consultant nurse) at sarah.pashley@nottshc.nhs.uk

The Epilepsy Community Clinic Service for people with Learning Disabilities within 2Gether NHS Trust

In rural Gloucestershire, the domiciliary model for epilepsy care was not suitable for regularly and closely monitoring some people's health and epilepsy. This was due to issues such as lack of privacy, missed appointments and the geographical size of the patch. Therefore, an epilepsy clinic service was set up. The aim was to provide closer monitoring of people with learning disabilities and epilepsy and, with the provision of reasonable adjustments, help to reduce the known health inequalities for this group. This is done by providing a personalised service with better partnership working.

Day centres and easily accessible venues were chosen to set up six community-based epilepsy clinics for people with learning disabilities. Initially, new referrals are seen at home to identify environmental risks, and then they and their carers are consulted about whether they would consider coming to clinics for follow up appointments. People with learning disabilities are sent pictorial, easy-read appointment letters offering 30/45-minute appointment slots at consistent appointment days/times. The aim of this is to maximise engagement for those with memory and literacy problems. Their carers, day centre staff and families are also invited if they wish to attend.

The clinics are run by a community nurse who has a specialist interest in epilepsy and is a nurse prescriber. During appointments she looks at people's general health (and undertakes pain assessments and other relevant assessments if appropriate). Seizure charting, summaries, variances that can affect seizure control and medication are looked at closely in the appointments.

In order to reduce seizures whilst maintaining a good quality of life, the type of

medication most suited to the individual's lifestyle and ability to swallow are identified. Measures to help people to take their medication consistently and strategies such as dosette boxes are organised. These have been shown to increase concordance. Epilepsy profiles are devised as part of the epilepsy care pathway and people have hand-held folders to empower them by involving them in their care. This information goes with them if they access neurology services or other generic services. Hospital traffic-light assessments are kept in the folder with a copy of their consultant's latest review letter. Individual risk management and rescue medication care plans are put together with the person who has learning disabilities to help them manage their seizures safely and effectively. The care plans are kept in the person's folder so they are available should their seizure control deteriorate. ID cards and advice about apps and other suitable aides, such as bed monitors, are also addressed to maintain independence.

Bone health is considered to minimise the risk of fragility fractures from some longer-term, anti-epileptic medications. Limited access to sunlight and sedentary lifestyles are risk factors. Advice about diet and exercise are given as well as the support needed to ensure that people have their vitamin D levels checked or access dual energy X-ray absorptiometry (DEXA) scans if appropriate.

Everybody prescribed midazolam has a care plan and carers also can access epilepsy and midazolam training in accordance with the joint epilepsy council guidelines. The plan is to extend the training to include a course for people with learning disabilities and epilepsy. This will aim to help them to understand and self-manage their condition.

There has been partnership working with generic services to improve the outcomes for people using this service. Reasonable adjustments made have included people taking their own drugs into hospital to avoid formulation changes, ward staff using pill timers, and alert systems being placed on hospital and GP records. The outcomes from this service are in line with NICE epilepsy guidance and have clearly indicated improved health outcomes from the specialist clinic. There are improvements in the recording of seizures and consistency of data collection for medical reviews. There is close monitoring of general health and people are informed about SUDEP and relevant safety measures are identified. Analysis of data from 2012/13 showed a 75% seizure reduction and reduced unplanned hospital admissions. The clinics allow regular contacts to be made and information is more consistent because it is gained from several parties all within the one appointment.

For further information please contact Penny Shewell (community nurse) at penny.shewell@glos.nhs.uk

South Cambridgeshire Community Learning Disability Team

South Cambridgeshire Community Learning Disability Team has developed several initiatives to improve the service offered to adults with learning disabilities and epilepsy. An epilepsy clinic is run jointly by a learning disability nurse and a psychiatrist. Both have additional expertise in managing epilepsy in adults with learning disabilities. The clinic was initially developed following the recognition that not all the information required by health professionals is always available when seeing a person with learning disabilities and epilepsy. The clinic occurs in the learning disability community team base on a regular basis. However, if necessary, as a reasonable adjustment, it can be run in homes in the community. All service users are regularly reviewed in the clinic, with the intervals between reviews determined by the users' clinical needs.

The clinic service provides:

- a pre-appointment questionnaire that is sent to service users a week before each appointment and enables full information to be gathered from across the person's support workers/carers, ensuring that all the relevant information is available at the clinic meeting. The topics covered include seizure description and frequency; anti-epileptic drug treatment, and possible side-effects. Service users or their support workers/carers also have an opportunity to highlight other issues they would like to address in the clinic meeting
- a SUDEP (sudden unexpected death in epilepsy) risk screen, which is worked through during the clinic meeting with service users and support workers/carers. It provides an opportunity to identify possible risk factors and to share information. If indicated, it leads to modification of management
- a forum to develop and discuss rescue medication protocols as part of an individual epilepsy care plan. In managing a person's epilepsy, there is close liaison with their GP, family and support staff
- a user satisfaction questionnaire, which has been developed by the team to audit service users and support workers/carers' views about the epilepsy clinic. These views inform the ongoing development of the clinic. Further information about the development of this accessible audit is available in Jones et al (2011)³⁶

The epilepsy clinic supports training about epilepsy in a variety of ways. The team provides training for support workers. They also regularly provide training to students from local medical and nursing schools, for junior doctor trainees in psychiatry and for professionals from other learning disability teams.

The team contributed to a DVD made for professionals working with people who have epilepsy and learning disabilities. The DVD was a joint project between Speaking Up (an advocacy group that is now part of Voiceability) and Cambridgeshire Disability Services. The DVD records people with a learning disability and epilepsy discussing their experiences of living with epilepsy. The resource is used in training.

For further information please contact Liz Jones or Howard Ring.

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Conclusion

People with learning disabilities are much more likely to have epilepsy than their non-disabled peers. Epilepsy is the main cause of avoidable hospital admissions and a common cause of death for people with learning disabilities. Diagnosis and assessment of epilepsy in people with learning disabilities is more difficult and fewer people with learning disabilities have well controlled epilepsy. Traditionally, people with learning disabilities and epilepsy have had suboptimal care and less access to specialist services. The provision of reasonable adjustments can help to improve the service they receive.

This report directs professionals, support workers and family carers to numerous resources that can be used to improve people's understanding of epilepsy and the investigations and treatments related to it. There are easy-read leaflets, films, epilepsy diaries, a range of apps, and examples of good practice at both individual and service levels.

Acknowledgements

We would like to thank everyone who contributed examples from practice to this report.

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Appendix A

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