



— B E L M A T T —  
HEALTHCARE TRAINING

# Understanding Epilepsy in older adults in the UK

# Introduction to Epilepsy



## 1. Epilepsy as a Neurological Condition:

- Epilepsy is a chronic disorder of the brain that affects the normal electrical activity, leading to recurrent seizures.
- It is not a single disease but a spectrum of disorders with various underlying causes and manifestations.
- Seizures in epilepsy can range from brief moments of unconsciousness or staring spells to convulsions and loss of control over bodily functions.

# Outline

- An overview of epilepsy, including its prevalence, types of seizures, and diagnostic criteria.
- Diagnostic testing for epilepsy
- Causes of epilepsy
- Antiepileptic Drugs and side effects
- Managing epilepsy in older adults.

## **2. Prevalence and Incidence of Epilepsy in the UK:**

- Epilepsy is one of the most common neurological conditions in the UK, with a significant impact on individuals and their families.
- According to estimates, around 600,000 people in the UK have epilepsy, representing approximately 1 in 100 individuals.
- The incidence of epilepsy varies across age groups, with a higher prevalence observed in children and older adults.
- Research suggests that epilepsy prevalence in the UK is slightly higher compared to other European countries.

Risk Factors for Seizures In Older Adults

RISK FACTOR	DEGREE OF RISK COMPARED TO HEALTHY OLDER ADULT
STROKE	20 times
DEMENIA	5 to 10 times
DEPRESSION	6 times
TRAUMA	3 times
ALCOHOL	3 times
INFECTION	3 times

## **3. Common Causes and Risk Factors:**

- Epilepsy can have various causes, and in about half of the cases, the underlying cause remains unknown (idiopathic epilepsy).
- Common causes of epilepsy include brain injuries, such as head trauma, strokes, infections, developmental disorders, genetic factors, and brain tumors.
- Certain risk factors, such as a family history of epilepsy, prenatal exposure to drugs or alcohol, and certain neurodevelopmental disorders, may increase the likelihood of developing epilepsy.



#### **4. Types of Seizures and Their Classification:**

- Seizures in epilepsy can be classified into two main categories: focal seizures (previously known as partial seizures) and generalized seizures.
  - **Focal seizures** originate in a specific part of the brain and can result in various symptoms, including altered consciousness, abnormal movements, sensory disturbances, or emotional changes.
  - **Generalized seizures** involve both hemispheres of the brain and can cause loss of consciousness, convulsions, muscle rigidity, or brief staring spells.

#### **5. Diagnostic Criteria and Epilepsy Syndromes:**

- The diagnosis of epilepsy is based on a comprehensive evaluation of the individual's medical history, seizure description, physical examination, and diagnostic tests.
- The International League Against Epilepsy (ILAE) provides guidelines and criteria for diagnosing epilepsy.
- Epilepsy syndromes are specific patterns of seizures and associated features that help classify and guide treatment decisions. Examples include childhood absence epilepsy, juvenile myoclonic epilepsy, and temporal lobe epilepsy.

# Identification : Could this be a seizure?

## *Recognizing Signs and Symptoms of Seizures*

- Staring into space
- Feeling disoriented
- Spells of dizziness
- Hallucinations
- Temporary changes in behavior, speech
- Temporary problems with language
- Intermittent memory problems
- Sense of having lost time
- Repetitive blinking or chewing
- Non-purposeful lip-smacking, picking movement
- Shaking or twitching of face, arms or legs
- Sudden falls
- Occasional 'fainting spells'
- Spells of unexplained fatigue
- Wandering

# Impact of Epilepsy on Quality of Life

- Epilepsy can significantly impact various aspects of an individual's life, including education, employment, social relationships, and overall quality of life.
- Studies have shown that individuals with epilepsy may face **educational challenges**, such as learning difficulties and school absenteeism, leading to lower academic achievements.
- **Employment rates** among people with epilepsy are lower compared to the general population, partly due to misconceptions, stigma, and concerns about seizure-related safety risks in the workplace.
- Epilepsy can also impact **social relationships**, leading to social isolation, anxiety, and depression.

# Health Disparities and Inequality in Epilepsy Care

- Research has highlighted disparities in epilepsy care and outcomes among different population groups within the UK, suggesting the presence of health inequalities.
- Certain ethnic minority groups, such as Black and South Asian communities, have been found to have a higher incidence of epilepsy, along with *increased challenges in accessing appropriate healthcare services*.
- There is a need to address these disparities through targeted interventions, culturally sensitive approaches, and improved access to epilepsy care for underserved populations.

# Diagnosis and Assessment

- Accurately diagnosing epilepsy is essential for providing appropriate treatment and support to individuals with the condition.
- We will explore the steps involved in diagnosing epilepsy, the significance of history-taking and observation, diagnostic tests and imaging techniques used in epilepsy, as well as the process of differential diagnosis to distinguish seizures from other conditions.

## **1. Steps Involved in Diagnosing Epilepsy:**

- The diagnosis of epilepsy is typically made by a healthcare professional, such as a neurologist or epileptologist, through a systematic evaluation of the individual's medical history, symptoms, and diagnostic tests.
- The initial step involves taking a **detailed history**, which includes gathering information about the *frequency, duration, and characteristics of seizures*, as well as *potential triggers or precipitating factors*.
- A thorough **physical examination** is conducted to identify any *neurological abnormalities* or signs that may provide clues about the underlying cause of seizures.

## **2. Importance of Accurate History-Taking and Observation:**

- ***Accurate history-taking is crucial*** for the diagnosis of epilepsy as it helps healthcare professionals understand the pattern of seizures and identify any specific features or triggers.
- Individuals are encouraged to ***Maintain a seizure diary***, noting the date, time, duration, and description of each seizure episode, as well as any associated symptoms or warning signs.
- ***Observations by witnesses or caregivers*** can provide valuable insights into the seizure presentation and aid in determining the type of seizure.



### **3. Diagnostic Tests and Imaging Techniques Used in Epilepsy:**

- Several diagnostic tests and imaging techniques are employed to support the diagnosis of epilepsy and assess the underlying cause of seizures.
- **Electroencephalogram (EEG):** EEG measures the electrical activity of the brain and is a fundamental test for diagnosing and classifying seizures. It helps identify abnormal brain wave patterns associated with epilepsy.
- **Video-EEG Monitoring:** This combines continuous EEG recording with video monitoring, allowing simultaneous documentation of seizures and their associated electrographic patterns.
- Neuroimaging: Magnetic resonance imaging (**MRI**) is commonly used to evaluate the brain structure and identify any structural abnormalities, such as tumors, vascular malformations, or scarring, that may be contributing to seizures.

#### **4. Differential Diagnosis and Distinguishing Seizures from Other Conditions:**

- Differential diagnosis involves distinguishing epilepsy from other conditions that may cause similar symptoms or seizure-like events.
- Some conditions that can mimic seizures include syncope (fainting), psychogenic nonepileptic seizures (PNES), sleep disorders, and movement disorders.
- Additional diagnostic tests, such as blood tests, genetic testing, and neuropsychological assessments, may be necessary to rule out other possible causes and confirm the diagnosis of epilepsy.

**Accurate diagnosis and differentiation** of seizures from other conditions enable healthcare professionals to develop an **appropriate management and treatment plan** tailored to the *individual's specific needs*. It also ensures that individuals with epilepsy receive timely and effective interventions, reducing the risk of misdiagnosis and unnecessary treatments.

# Antiepileptic Drugs (AEDs)

Antiepileptic drugs (AEDs) play a crucial role in the management of epilepsy by reducing the frequency and severity of seizures.

## 1. Overview of Common AEDs Used in the UK:

- There are several AEDs available in the UK, each with its own efficacy and safety profile.
- Commonly prescribed AEDs include carbamazepine, valproate, lamotrigine, levetiracetam, and oxcarbazepine, among others.
- The choice of AED depends on factors such as the type of seizures, epilepsy syndrome, age, gender, comorbidities, and individual response to specific medications.

## **2. Mechanisms of Action and Side Effects:**

- AEDs act through various mechanisms to suppress abnormal neuronal activity and prevent the occurrence of seizures.
- For example, sodium channel blockers (e.g., carbamazepine) reduce abnormal electrical discharges, while GABA-enhancing drugs (e.g., valproate) increase inhibitory neurotransmission.
- AEDs can have potential side effects, which vary depending on the medication. Common side effects include drowsiness, dizziness, cognitive impairment, gastrointestinal disturbances, and skin rashes.
- Some AEDs may also have specific risks, such as the potential for teratogenic effects (e.g., valproate) or cognitive side effects (e.g., topiramate).

### **3. Individualizing AED Therapy and Treatment Options:**

- AED therapy should be individualized based on several factors, including seizure type, epilepsy syndrome, comorbidities, and the individual's lifestyle and preferences.
- Treatment goals include achieving seizure control, minimizing side effects, improving quality of life, and considering long-term management.
- In some cases, combination therapy (using multiple AEDs) may be required to achieve optimal seizure control.
- Newer AEDs with different mechanisms of action continue to be developed, expanding the treatment options available to individuals with epilepsy.

#### **4. Adherence to Medication and Monitoring Therapeutic Levels:**

- Adherence to prescribed AEDs is crucial for achieving effective seizure control and preventing breakthrough seizures.
- Healthcare professionals should **educate individuals about the importance of taking medication** as prescribed and provide strategies to improve adherence.
- **Regular monitoring of therapeutic drug levels** (when applicable) helps ensure that the individual is receiving an adequate dose for optimal seizure control.
- **Therapeutic drug monitoring** is particularly important for AEDs with narrow therapeutic indices, such as phenytoin or phenobarbital.

# Anti Epileptic Drugs

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**Levetiracetam** (Keppra): Levetiracetam is one of the newer AEDs and is often well-tolerated by older individuals. It has a relatively low potential for drug interactions.

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**Lamotrigine** (Lamictal): Lamotrigine is another commonly prescribed AED, and evidence suggests that it may be effective in older adults with epilepsy.

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**Valproate** (Depakote): Valproate is an older AED that is effective against different seizure types. However, it may have more side effects and drug interactions compared to newer AEDs, and its use in older adults should be carefully considered.



# Anti Epileptic Drugs

- **Carbamazepine** (Tegretol): Carbamazepine is an older AED that is still used in certain cases, but its use in older adults requires close monitoring due to potential side effects and drug interactions.
- **Oxcarbazepine** (Trileptal): Oxcarbazepine is a newer AED that is structurally related to carbamazepine but may have a more favorable side effect profile.
- **Phenytoin** (Dilantin): Phenytoin is an older AED that may be used in some cases, but it has a higher risk of side effects and drug interactions, and its use in older adults should be carefully considered.

- It is crucial for healthcare professionals to **regularly review the medication regimen** of older persons with epilepsy to monitor for any potential side effects, drug interactions, or changes in their overall health.
- **Treatment plans should be tailored** to each individual's specific needs and adjusted as necessary based on their response to the medication and any changes in their health status.
- Since epilepsy management in older persons can be complex, it is essential for healthcare professionals to consider the latest clinical guidelines, evidence-based practices, and potential legislative restrictions when prescribing AEDs for this population. They should also **collaborate** closely with the patient, their caregivers, and other healthcare providers to ensure the best possible outcomes in managing epilepsy in older individuals.

# Managing Epilepsy Effectively

Managing epilepsy effectively involves a comprehensive approach that includes lifestyle modifications, self-management strategies, identification and avoidance of seizure triggers, developing seizure action plans, and implementing safety measures.

## **1. Lifestyle Modifications and Self-Management Strategies:**

- Encouraging a healthy lifestyle can help individuals with epilepsy better manage their condition. This includes:
  - Adequate sleep: Ensuring a regular sleep schedule and addressing sleep-related issues can reduce seizure frequency.
  - Stress management: Employing stress-reducing techniques, such as relaxation exercises or mindfulness, can be beneficial.
  - Balanced diet: Maintaining a well-balanced diet and avoiding triggers like excessive caffeine or alcohol.
  - Regular exercise: Engaging in regular physical activity, based on individual capabilities, can contribute to overall well-being.

## **2. Seizure Triggers and Their Avoidance:**

- Identifying individual seizure triggers is crucial for managing epilepsy effectively. Common triggers may include:
  - Lack of sleep or irregular sleep patterns
  - Emotional stress and anxiety
  - Hormonal changes (in women)
  - Flickering lights or specific visual patterns (photosensitivity)
  - Certain medications or drug interactions
- Once triggers are identified, individuals can take proactive steps to avoid or minimize exposure to them, thereby reducing the likelihood of seizures.

### **3. Developing Seizure Action Plans and Emergency Response Protocols:**

- Seizure action plans outline specific steps to be taken during and after a seizure, providing guidance to individuals, caregivers, and healthcare professionals.
- Action plans typically include:
  - Description of seizure types and typical duration
  - Medication details and instructions on administering rescue medication, if prescribed
  - Emergency contact information and instructions for seeking medical assistance
  - Post-seizure care and recovery guidelines
- It is important to regularly review, and update seizure action plans based on individual needs and any changes in seizure patterns or treatment.

#### **4. Safety Measures and Seizure Precautions:**

- Implementing safety measures and seizure precautions can help minimize the risk of injury during seizures. These may include:
  - **Creating a safe environment:** Removing sharp objects or potential hazards, securing furniture, and ensuring a clear space during activities.
  - **Using assistive devices:** Wearing helmets or protective gear during activities that pose a higher risk of injury.
  - **Educating family, friends, and caregivers:** Providing information on seizure first aid, including proper positioning, protecting the head, and not restraining the person during a seizure.
  - **Raising awareness:** Informing teachers, employers, and other relevant individuals about the person's condition and necessary accommodations, if required.

- By incorporating lifestyle modifications, identifying and avoiding seizure triggers, developing seizure action plans, and implementing safety measures, individuals with epilepsy can take an active role in managing their condition and reducing the impact of seizures on their daily lives.
- Collaboration with healthcare professionals and education of family members, friends, and caregivers are also crucial for effective epilepsy management.

# Seizure first aid and appropriate emergency management

**Seizure first aid and appropriate emergency management** are vital skills for individuals, caregivers, and bystanders to ensure the safety and well-being of someone experiencing a seizure.

## 1. Understanding Different Types of Seizures:

- Seizures can manifest in various ways, and it is important to recognize the different types to provide appropriate aid. Common types of seizures include:
  - **Generalized tonic-clonic seizures:** Involves loss of consciousness, convulsions, and stiffening of the body.
  - **Absence seizures:** Brief staring spells with a temporary loss of awareness.
  - **Focal seizures:** May involve altered consciousness, abnormal movements, sensory disturbances, or emotional changes, depending on the part of the brain affected.

Seizures in older persons can present differently compared to younger individuals due to age-related changes in the brain and underlying health conditions. **Some of the differences in the presentation of seizures in older persons include:**

- **Altered Consciousness:** Older adults may experience subtle changes in consciousness during a seizure, making it less apparent that they are having a seizure. They may appear confused, disoriented, or dazed, which can be mistaken for other conditions like dementia or cognitive impairment.
- **Absence of Convulsions:** While generalized tonic-clonic seizures (previously known as grand mal seizures) are common in younger individuals and involve convulsions, older persons may have seizures without such dramatic motor manifestations. Seizures in older adults may present as *brief staring spells or sudden periods of unresponsiveness* (absence seizures).
- **Focal Seizures:** Focal seizures are more common in older adults, and they may involve abnormal movements, sensory disturbances, emotional changes, or altered consciousness. These focal features can be mistaken for stroke or other neurological disorders.

# Seizures in Older Patients



**Auras:** Older individuals with epilepsy may experience auras before a seizure, which are warning signs or premonitions of an impending seizure. Auras can vary widely and may involve visual, auditory, olfactory, or sensory sensations.



**Postictal State:** After a seizure, older adults may experience a more prolonged postictal state, characterized by confusion, drowsiness, or memory difficulties. This post-seizure state can last longer in older individuals compared to younger ones.



**Increased Risk of Falls:** Seizures in older persons can pose a higher risk of falls and injuries due to age-related frailty and vulnerability. Falls may lead to fractures or other complications, making it crucial to take appropriate safety precautions.



**Underlying Health Conditions:** Older adults often have coexisting medical conditions, such as heart disease, hypertension, or diabetes, which can complicate the presentation of seizures and influence treatment decisions.

## **2. Recognizing and Responding to Seizures Appropriately:**

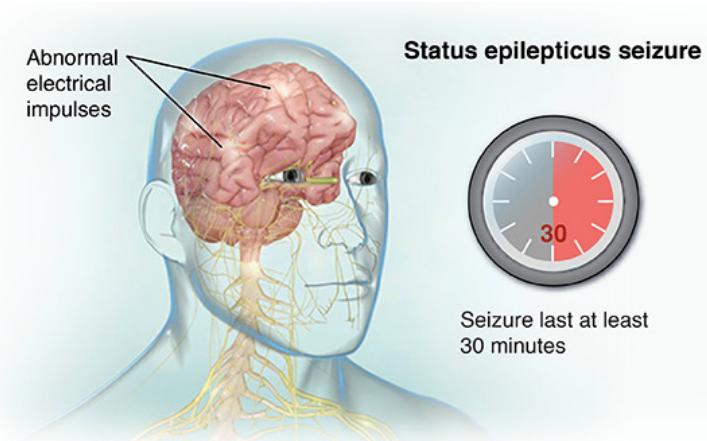
- Remain calm and stay with the person experiencing the seizure. Do not panic or restrain them.
- Protect the person from injury by moving away hazardous objects and creating a safe space.
- Time the duration of the seizure, as this information can help medical professionals later.
- Do not attempt to insert anything into the person's mouth during the seizure. Contrary to popular belief, it is not necessary and can cause harm.

## **3. Administering First Aid During Seizures:**

- Ensure the person's safety by gently guiding them to a lying or supported position, if possible.
- Cushion their head with a soft object or clothing to prevent injury.
- Loosen tight clothing around their neck to facilitate breathing.
- Turn the person onto their side (recovery position) after convulsions stop to prevent choking on saliva or vomit.
- Stay with them until they regain full consciousness and are fully alert.

#### **4. When to Seek Emergency Medical Assistance:**

- Most seizures are self-limiting and stop on their own. However, emergency medical assistance should be sought in the following situations:
  - The seizure lasts longer than five minutes (status epilepticus).
  - The person has difficulty breathing or turns blue.
  - Multiple seizures occur without regaining consciousness in between.
  - Injury occurs during the seizure.
  - The person is diabetic or has a known heart condition.



# Heart Conditions and Diabetes in Older Patients with Epilepsy

- Managing Underlying Medical Conditions
- Identifying and Treating Triggers
- Preventing Seizure-Related Injuries
- Managing Medications
- Assessing Neurological Health
- Addressing Potential Complications

It is crucial to educate individuals, caregivers, and bystanders about seizure first aid and emergency management. By understanding the different types of seizures, recognizing and responding appropriately, administering first aid, and knowing when to seek emergency medical assistance, individuals can contribute to ensuring the safety and well-being of those experiencing seizures

# **Support Systems and Resources in the UK**

Accessing appropriate support systems and resources is essential for individuals with epilepsy to manage their condition effectively. In this module, we will explore the epilepsy support organizations and networks available in the UK, accessing specialist epilepsy services and centers, understanding the role of healthcare professionals such as epilepsy nurses, neurologists, and epilepsy specialist nurses, as well as the legal rights and protections for individuals with epilepsy.

## **1. Overview of Epilepsy Support Organizations and Networks in the UK:**

- The UK has several epilepsy support organizations and networks dedicated to providing information, resources, and support to individuals with epilepsy and their families.
- Examples include Epilepsy Action, Epilepsy Society, Young Epilepsy, and The Daisy Garland, among others.
- These organizations offer helplines, online communities, educational materials, and advocacy initiatives to raise awareness and promote the well-being of individuals with epilepsy.

## **2. Accessing Specialist Epilepsy Services and Centers:**

- Specialist epilepsy services and centers play a crucial role in the comprehensive management of epilepsy. They offer specialized care, diagnostic evaluations, treatment options, and ongoing support.
- Individuals can access these services through referral from their primary care physician or neurologist. Some services may require a referral from a specialist epilepsy nurse or other healthcare professionals.

### **3. Understanding the Role of Epilepsy Nurses, Neurologists, and Epilepsy Specialist Nurses:**

- Epilepsy Nurses: Epilepsy nurses are specialized healthcare professionals who provide education, support, and guidance to individuals with epilepsy and their families. They assist in managing medication, monitoring seizure activity, and addressing concerns related to epilepsy.
- Neurologists: Neurologists are medical doctors who specialize in the diagnosis and treatment of neurological disorders, including epilepsy. They provide expertise in the management of epilepsy, conduct diagnostic evaluations, and prescribe appropriate medications or treatment options.
- Epilepsy Specialist Nurses: Epilepsy specialist nurses are registered nurses with specialized training in epilepsy care. They work alongside neurologists to provide comprehensive care, education, and ongoing support to individuals with epilepsy.

#### **4. Legal Rights and Protections for Individuals with Epilepsy:**

- In the UK, individuals with epilepsy are protected by various legal rights and provisions to ensure equal opportunities and prevent discrimination.
- The **Equality Act 2010** prohibits discrimination on the grounds of disability, including epilepsy, in various areas such as employment, education, and provision of goods and services.
- The **Disability Discrimination Act (DDA)** provides additional protections, requiring reasonable adjustments to be made to accommodate individuals with disabilities, including epilepsy.
- It is important for individuals with epilepsy to be aware of their rights, seek legal advice if necessary, and advocate for their needs when accessing education, employment, healthcare, and other services.

By accessing epilepsy support organizations and networks, utilising specialist epilepsy services, understanding the roles of healthcare professionals, and being aware of legal rights and protections, individuals with epilepsy can access the necessary resources and support to effectively manage their condition and enhance their quality of life.

## CONTACT INFO



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# Learning disabilities in older adults



# Lecture Outcomes

By the end of this session, you will be able to:

- Describe the symptoms of specific learning disabilities.
- Understand how people with learning disabilities in the community are cared for.
- Management of medical conditions

# Categorisation

- Learning Disabilities:

1. Specific learning disorder

2. Intellectual disabilities

# DSM-5

- This neurodevelopmental disorder involves difficulties learning and using academic skills.
- “Specific Learning Disorder” (SLD) has become the umbrella term for mathematics, reading, and written expression disorders in the updated DSM-5.

# DSM-5

- Diagnostic criteria include difficulty with word reading, understanding the meaning of what is read, word meaning, spelling, written expression, number use and calculation, and mathematical reasoning.
- Combines diagnoses, which were separate in DSM-IV, of reading disorder, disorder of written expression, mathematics disorder, and learning disorder not otherwise specified

## Criterion A

One of the following symptoms must be present and persisted for at least 6 months despite the provision of intervention that targets the difficulties:

- inaccurate or slow and effortful word reading;
- difficulty understanding what is read;
- spelling difficulties;
- difficulties with written expression;
- difficulties mastering number sense, number facts, or calculation; or
- difficulties with mathematical reasoning.

## Criterion B

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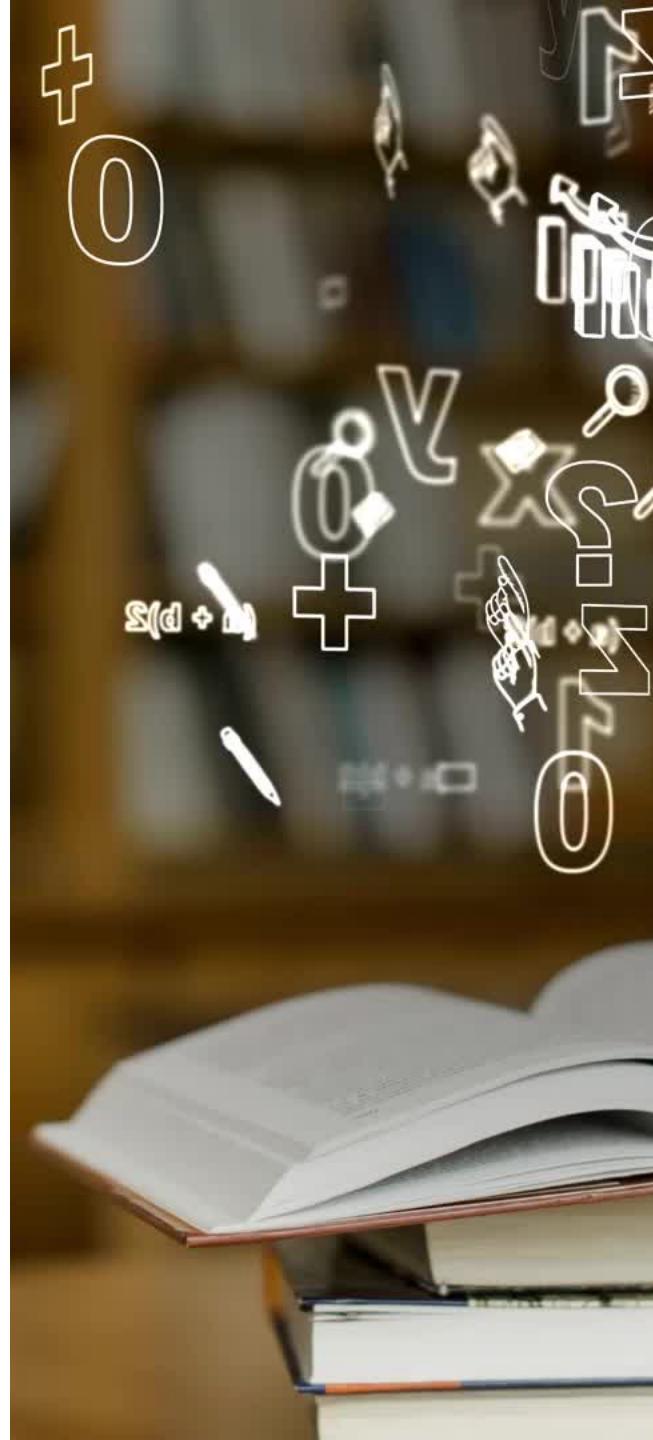
Requires that the affected academic skills be confirmed and quantified as being below those expected for chronological age, **and**

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cause significant impairment in academic or occupational performance or in activities of daily living.

## Criterion C

- This criterion specifies the age at onset of the learning difficulties
- The disorder begins during the years of formal schooling.



# Criterion D

- Learning difficulties are ‘specific’ in that they are not attributable to intellectual disabilities, uncorrected auditory or visual acuity deficits, other major psychiatric or neurological disorders etc.

## Current Severity

- clinicians are required to specify the current severity of the learning disabilities (mild, moderate, severe).
- Severity specifiers for SLD are based on an admixture of the range of learning difficulties and the likelihood of gaining proficiency in the academic skills given specialized teaching, accommodations, or support services (at school, home, or workplace).

## Specific types and DSM code

Specific learning disorder ICD-10  
code: F81.0

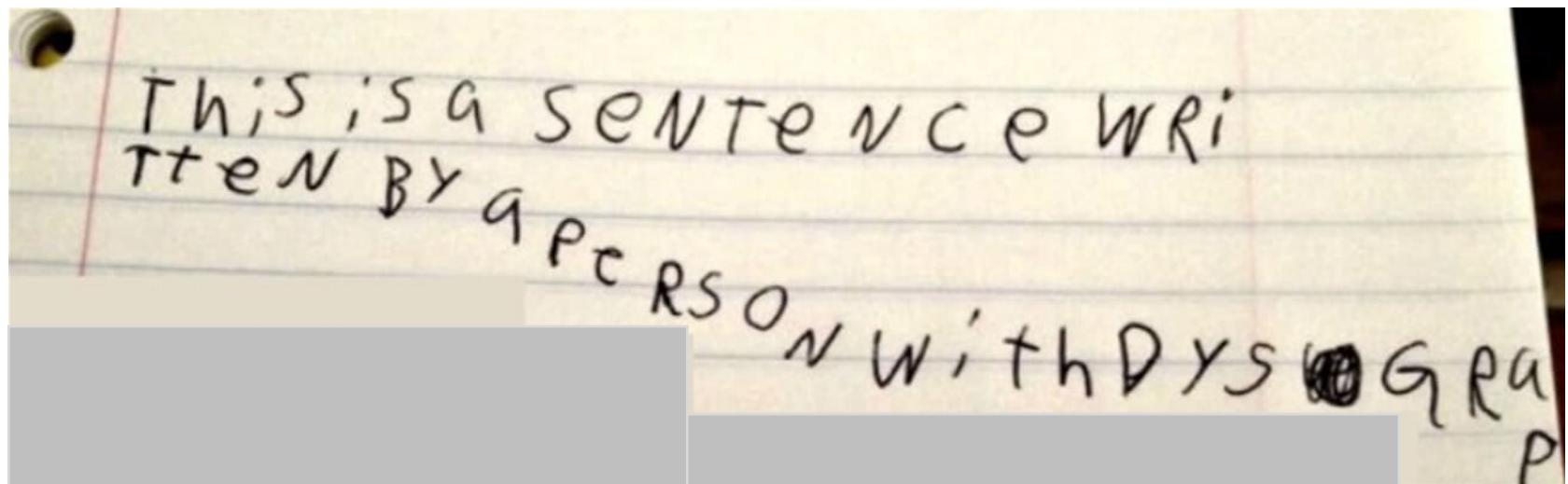
- with impairments in reading (315.0)
- with impairments in written expression (315.2)
- with impairments in mathematics (315.1)



# SLD with impairment in reading

- According to the ICD-10, dyslexia is “*a disorder manifested by difficulty learning to read despite conventional instruction, adequate intelligence and sociocultural opportunity*” (WHO, 1993)
- Word reading accuracy
- Reading rate or fluency
- Reading comprehension
- Prevalence: 3-17.5% in school-aged children
- Greater prevalence in boys (60-80%)

# SLD with impairment in written expression (dysgraphia)

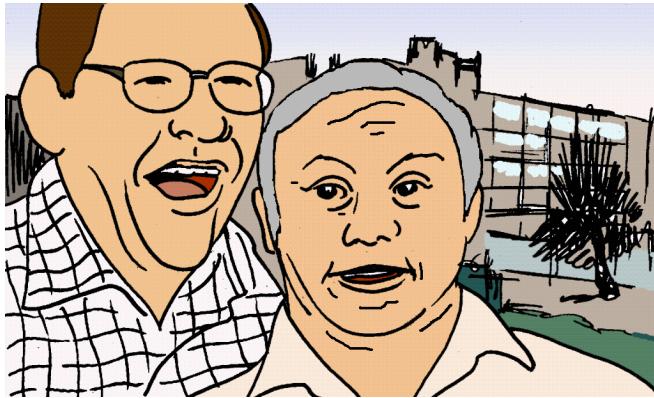


- Spelling accuracy
- Grammar and punctuation accuracy
- Clarity or organization of written expression



## SLD with impairment in mathematics (dyscalculia)

- “*A condition that affects the ability to acquire arithmetic skills*” (UK DfES, 2001)
- Number sense
- Memorization of math facts
- Accurate or fluent calculation
- Accurate math reasoning
- Affects ~5%
- Less is known about dyscalculia compared with dyslexia.



# Care and support for older people with learning disabilities

## NICE guideline

# Why is this relevant to primary care?

- People with learning disabilities can struggle with healthcare settings for a variety of reasons including:
  - Problems with understanding the language of illness and health (and reliance on written information, including appointment information).
  - Challenges with communicating their symptoms, history, and needs.
  - Concerns and anxieties about their previous experiences in healthcare.
  - Having complex physical needs.
- Diagnostic overshadowing (where symptoms of ill health are misattributed by health professionals to the person's inherent learning difficulty).
- Negative stereotypes and bias against people with learning difficulties or Autism Spectrum Disorders.
- This training module outlines the skills, knowledge, and behaviours which constitute competence when interacting with people with learning disabilities and autism spectrum disorder.

# Why is this relevant to primary care?

- It is based on the core competencies framework which comprises a range of capabilities:
  - Understanding learning disabilities and autism
  - Personalised care and support
  - Physical and mental health and well-being
  - Risk, legislation, and safeguarding
  - Leadership and management, education, and research
- Each capability comprises the key outcomes of learning or performance. Some of these may be more relevant to some health professionals than others as not all capabilities are essential for all roles.
- It is important to recognise that tier 2 training may involve additional education and learning opportunities. This is offered as a recorded webinar.

# What the guideline covers



**Choice and control**  
slides 5-9



**Support from health services**  
slides 20-26



**Local services**  
slides 10-11



**Care for health problems**  
slides 27-31



**Changing needs**  
slides 12-15



**Planning end of life care**  
slides 32-33

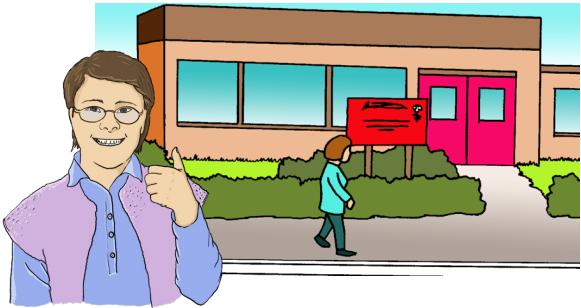


**Planning support**  
slides 16-19



**Staff skills**  
slide 34

# 5. Choice and control



Make sure older people with learning disabilities can use the same services as everyone else.



Services mean things like health, housing and social care.

It also means getting support as a carer if they look after a family member.



# 6. Choice and control



Give people clear information about services.

Tell them what different services are for and how to use them.



Make sure they understand this information.

Provide an independent **advocate**.  
(An advocate helps people speak up.)



# 7. Choice and control



Support people to communicate in the way they prefer.

A person's communication needs might change as they get older.

Ask people regularly if they need more support.



# 8. Choice and control



Support people to make their own decisions.

Make sure they always have a say, even if they need help to make decisions.



Don't put the views of family, carers or others before the views of the person themselves.



# 9. Choice and control



Involve families and carers, if people agree.

Involve everyone in the person's **support network**.

(The support network is everyone who helps the person, like friends, family and carers.)

Check regularly if families and carers are happy and able to give this support.

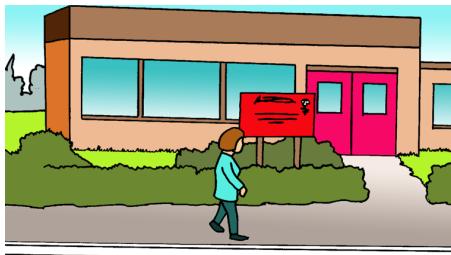


# 10. Local services



Find out what services people with learning disabilities need in their local area.

Think about what they need, now and when they are older.



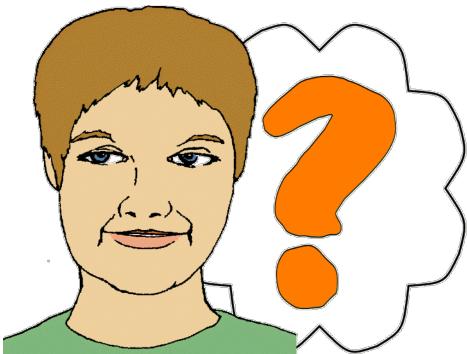
Provide these services close to home and help people use them.



# 11. Local services

## What people need

- Support to live where they choose
- Help to use health services
- One person to talk to for all advice
- Help for families, like respite breaks
- Ways to stay active in the community
- Ways to meet people and make friends
- Help to get around



# 12. Changing needs



As someone gets older their needs might change.

Offer people regular **assessments** of their care and support.

(An assessment means finding out what people need.)

Assessments should be done by staff who know the person well.



# 13. Changing needs



Staff doing **assessments** should ask if the person cares for other family members.

Offer a carer's assessment to support them as a carer.

Think about how caring will affect them when they are older.



# 14. Changing needs



Staff doing **assessments** should look out for changes as people get older.



Changes could be due to a health problem, not because of their learning disability.



They could be feelings, like being worried or sad.

They could be physical problems like pain or losing weight.



# 15. Changing needs



Staff doing **assessments** should find out what help families and carers need to support the person.

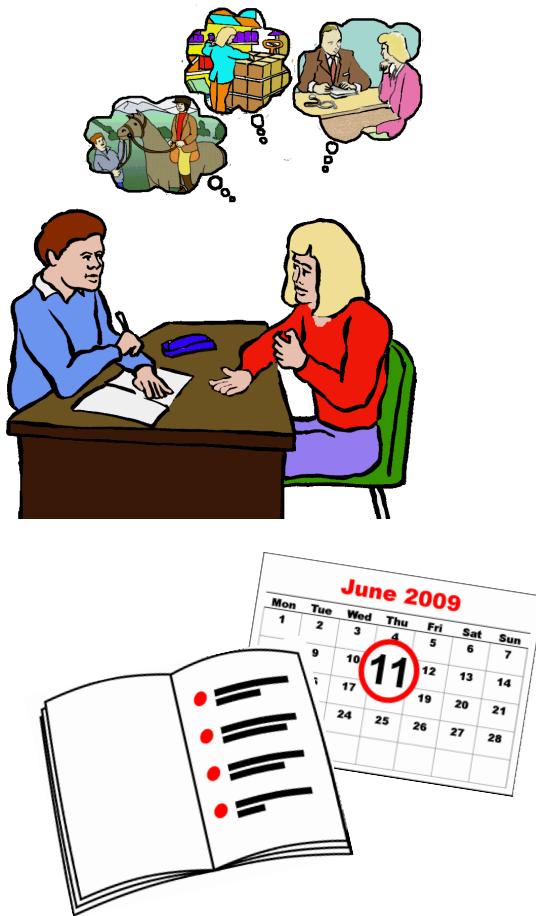
Offer them a carer's assessment.

Ask if they need more help at least once a year or when something new happens.

Tell them how to register as a carer.



# 16. Planning support



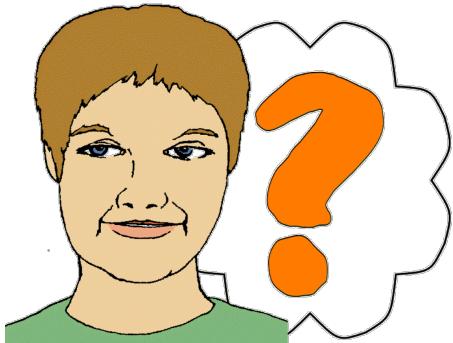
Staff who know the person well should help them write a plan.

Plan what support the person and their family need now.

Also write a plan for the future.

Ask if they are still happy with the plan once a year or when something new happens.

# 17. Planning support



## What to put in the plan

- Where people might want to live
- Who will support them
- Who will help them make decisions
- Who will help them with money
- Who to talk to if something goes wrong
- Decisions about care near the end of their life



# 18. Planning support



Help people stay in their home as they get older if they want to.

Put new equipment in their house if they need it, like a lift or support phone.



If people live at home with help from support staff, check at least once a year if their needs have changed.



# 19. Planning support

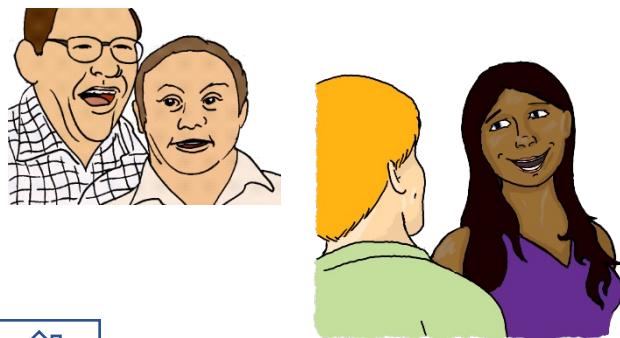


If a person wants to move to residential care help them plan this early.

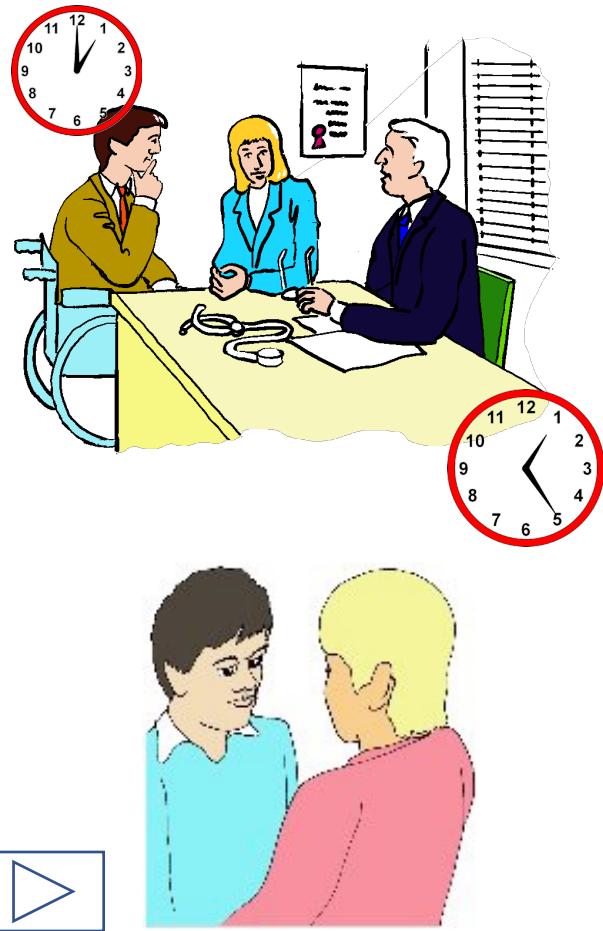
Involve family or an **advocate**.

Help the person visit the place before they move there.

Plan how they can keep in touch with their **support network** and make new friends.



# 20. Support from health services



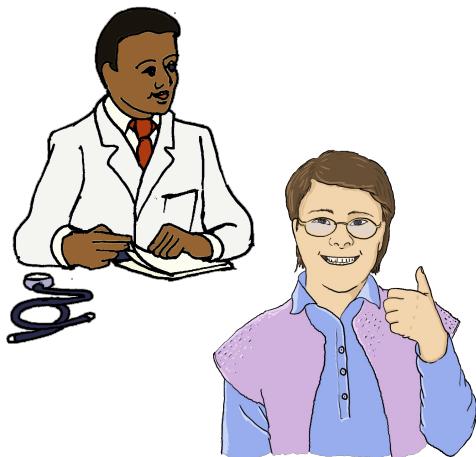
Give people longer visits with the doctor.

Someone who knows the person well should go with them.

If the person needs to be examined try to do it somewhere they know.

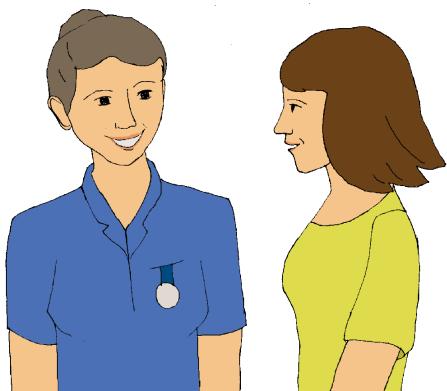
Make sure the person always knows what is happening.

# 21. Support from health services



Try to make sure people see a doctor or nurse they know.

One staff member should be in charge of supporting people and their families.



They could be from the community learning disability team or a nurse with experience in learning disabilities.



## 22. Support from health services



Health staff should always know that someone has a learning disability.

It should be written in their medical record.



The record should also show the person's communication needs and other needs.



# 23. Support from health services



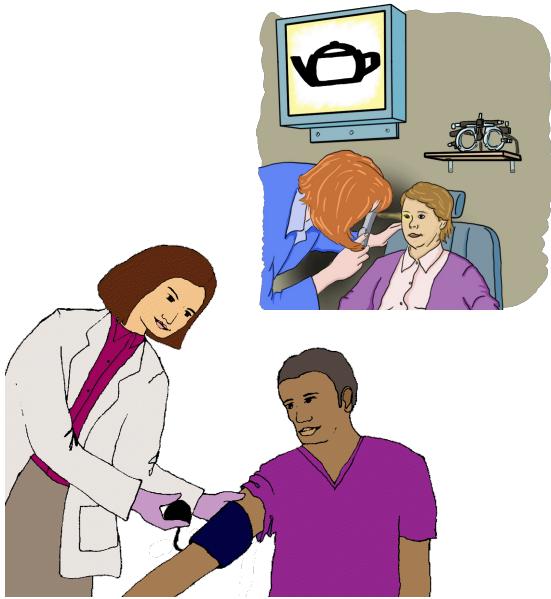
Every healthcare team should have a staff member who knows how to work with people with learning disabilities.

They should talk to people with learning disabilities to find out their needs.

Share this information with other staff to help them support people.



# 24. Support from health services



Offer people the same health checks and **screening tests** as other older people.

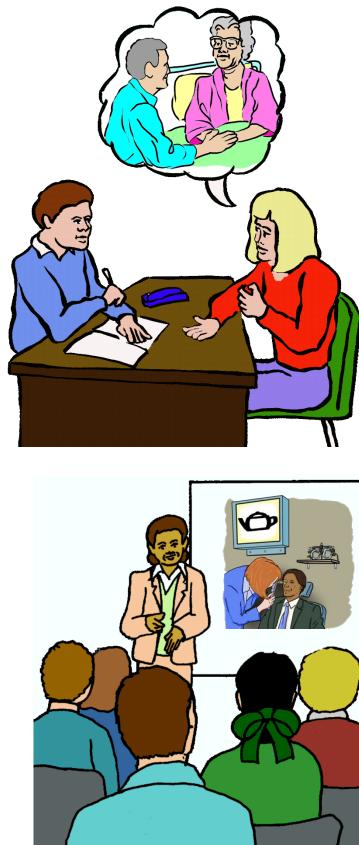
(Screening tests check for health problems even in people who feel well.)

Ask people if they see a dentist.

Ask if they know how to look after their teeth.



# 25. Support from health services



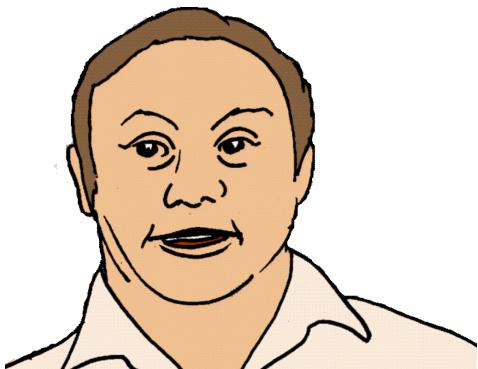
Give people advice about keeping well as they get older.

Tell people what changes to look out for in their health.

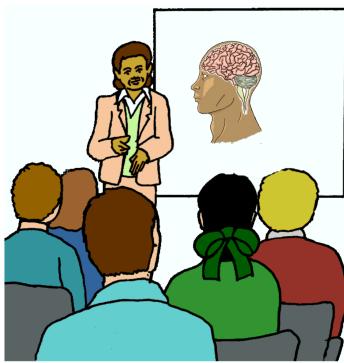
Teach people and their families and carers how to spot problems that might need treatment.



# 26. Support from health services



**Dementia** can happen earlier in people with learning disabilities.  
(Dementia is an illness that affects memory and how you think and feel.)



Give families information and support about signs of dementia.

Make sure support staff know how to spot dementia.



# 27. Care for health problems



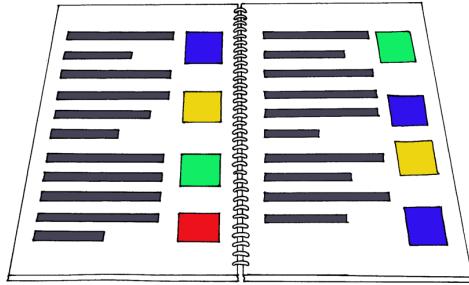
If someone has a health problem all staff who support them should keep in touch about the person's care.

Involve the person and their family too.

Help the person keep active and well by doing things they enjoy, like sports and hobbies.



# 28. Care for health problems



Give the person and their family information about their health problem.

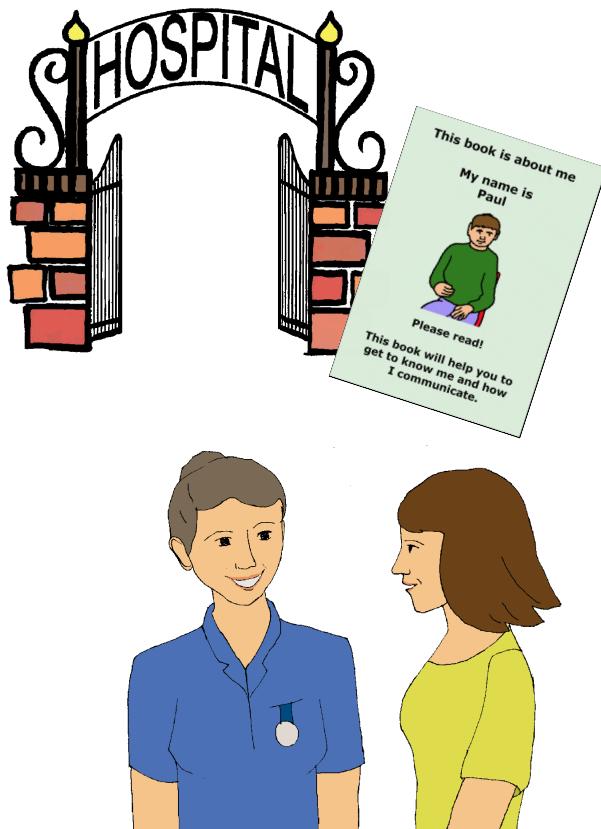
Make sure they understand it.

Talk to them about treatments and medicines.

Teach them how to take and look after their medicines.



# 29. Care for health problems



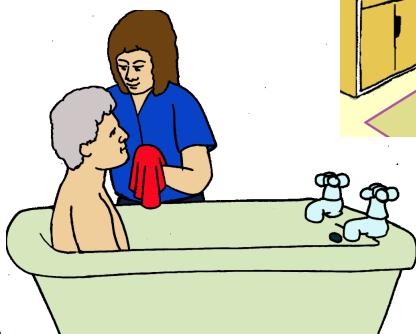
If someone needs to go to hospital staff should help them and their family plan this.

Find out what support they will need.

Help them visit the hospital first and meet staff who will be looking after them.



# 30. Care for health problems



A family member or carer should be able to stay with the person in hospital.

They should be able to sleep there too.

Staff should give the person the same care even if they have a family member or carer with them.



# 31. Care for health problems



Involve people and their families in planning when to leave hospital.

Hospital staff should talk to the person's local care team.

Everyone should work together to care for the person.

Think about what support their family needs too.



# 32. Planning end of life care



Help people plan early the care they want near the end of their life.

Help people decide where to have care.

Check regularly who the person wants to involve in planning.

Involve everyone who is important to the person.



# 33. Planning end of life care



Staff in different services should work together to give people the right care near the end of their life.



Staff should get to know people to understand their needs.



Listen to family and carers because they know the person best.



# 34. Staff skills



Staff working with older people should know how to support older people with a learning disability.



Learning disability staff should know how to support people as they get older.



Staff in these services should teach each other.





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