



DEMENTIA & THE FAMILY... BLACK HISTORY MONTH, 2023

Topic:

Why Dementia Care during Black History Month?



We must try to break down the barriers that frequently impede social cohesion, diversity, inclusion, and equality, but especially in “social and healthcare provisions”.

Every October, the United Kingdom observes Black History Month. It allows everyone to share, enjoy, and comprehend the significance of black ancestry and culture. For generations, people of African and Caribbean descent have formed an important part of British history. Campaigners, on the other hand, believe that their contributions to society are frequently disregarded or misunderstood. So, we want to use this opportunity not only to discuss the struggles and contributions of black people in the UK, but also to promote “health matters”, and today we focus on Dementia and Epilepsy.

The 2021 Census data shows that:

- The total population of England and Wales was 59.6 million
- 2.4 million people (4.0%) were from black ethnic groups – 1.5 million of those identified with the black African ethnic group (2.5%), and 0.6 million with the black Caribbean ethnic group (1.0%)
- 1.7 million people (2.9%) had mixed ethnicity – 0.5 million of those identified with the mixed white and black Caribbean ethnic group (0.9%), and 0.5 million with the mixed white and Asian ethnic group (0.8%)
- More than 25,000 older black and minority ethnic (BME) people live with dementia in the UK, in part due to vascular risk factors such as hypertension often found in African-Caribbean and South Asian UK populations.



Chinno Wills-Cole
Co-founder & CEO, Decew



Mrs. Cathy Adadevoh
Specialist Epilepsy Nurse

▪ **Identifying services that support PWD**

Charities and voluntary organisations provide valuable help and advice on their websites and via their helplines, for example:

1. Alzheimer's Society – Dementia Connect support line 0333 150 3456.
2. Age UK – advice line 0800 678 1602 (free)
3. Independent Age – helpline 0800 319 6789 (free)

▪ **Support for carers**

Carers need help also, which could come in the form of information leaflets, a support group, or connecting with other carers online. Becoming a carer often entails taking on new roles, chores, and obligations, as well as a shift in the connection with the individual diagnosed with dementia.

Carers often neglect their own health and can become isolated.

▪ **The impact of a dementia diagnosis on the family**

When a relative is diagnosed with dementia, family members take up new roles. Sons and daughters may become carers, and spouses and wives may see their responsibilities shift as well. They frequently find themselves in the position of a primary carer. It also affects their social life, psychologically, financially, emotionally, and lots more.

▪ **Focus on supporting families to better understand Dementia and other health needs (E.g. Epilepsy)**

What is Dementia?

Dementia is a term describing a range of progressive neurological disorders; an illness caused by damage to the brain. It can also be defined as a “syndrome” occurring as a result of a disease of the brain, which is usually chronic or progressive in nature. Currently, there is no cure.

Dementia can affect several areas of a person’s life, making it difficult to function as usual. Some of these areas include memory, concentration, thinking, behaviour, judgement, comprehension, calculation, language, and learning.

These impairments often occur alongside changes in “emotional control, social behaviour or motivation” (Dening, 2015).

There are over 100 subtypes of dementia, but the most commonly known are;

- Alzheimer’s disease
- Vascular dementia
- Lewy Bodies dementia
- Frontotemporal dementia
- Mixed dementia.

KEYNOTE:

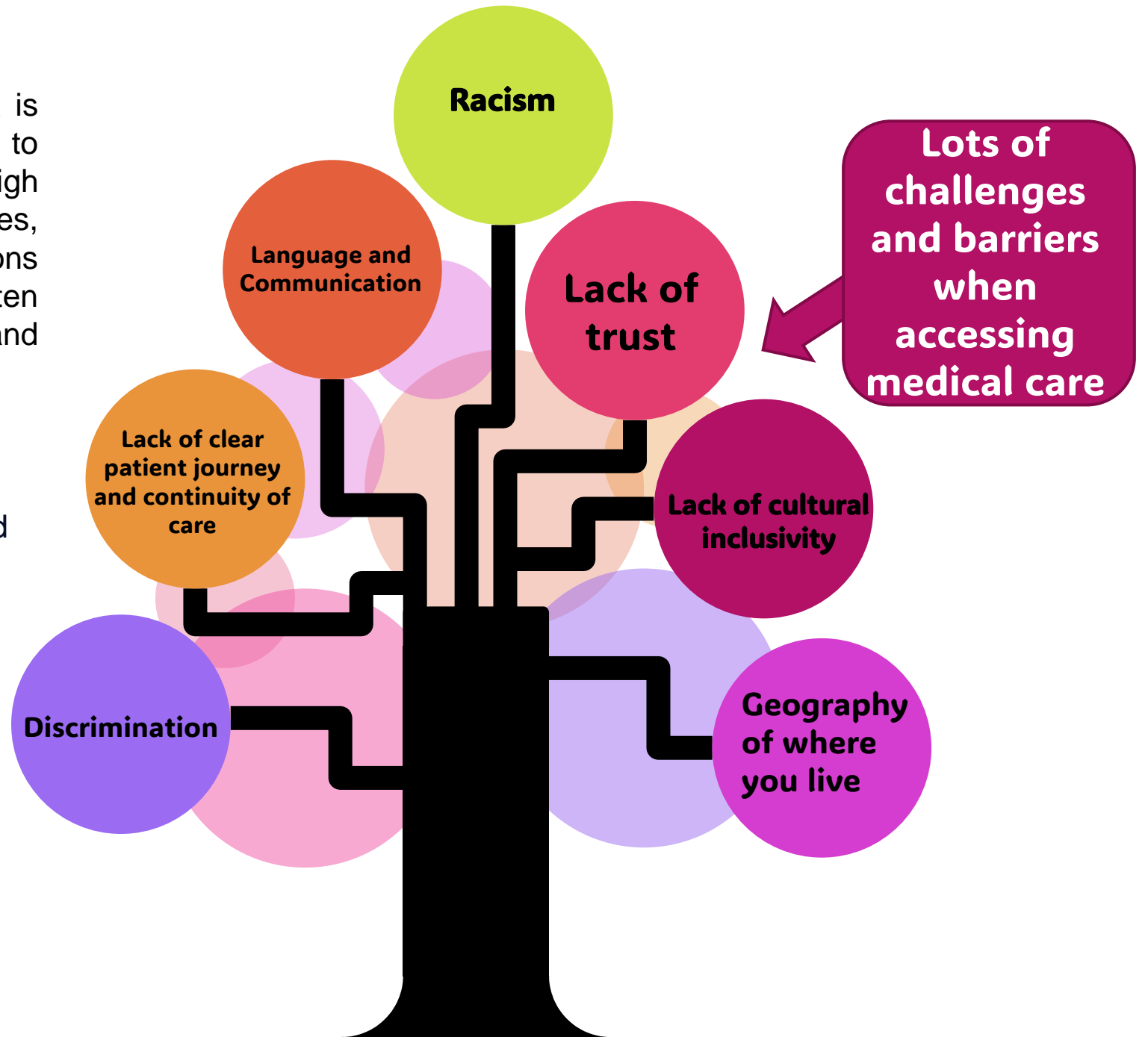
An African or African Caribbean in the UK is more likely than people from other cultures to have certain health conditions, including high blood pressure (hypertension), diabetes, stroke, and lots more. Most of the conditions that are common in the black community often form some of the risk factors for dementia and many other life-limiting health conditions.

▪ Some Barriers

Lack of a permanent address, poor living and working conditions, isolation, **uncertain immigration status**, exploitation, poverty, and hunger, can prevent someone from seeking help for health issues.

▪ Some Solutions:

Better data, research, and participation in clinical trials.



How willing would you be to have each of the following tests to help identify your risk of developing Alzheimer's disease? (No treatments)

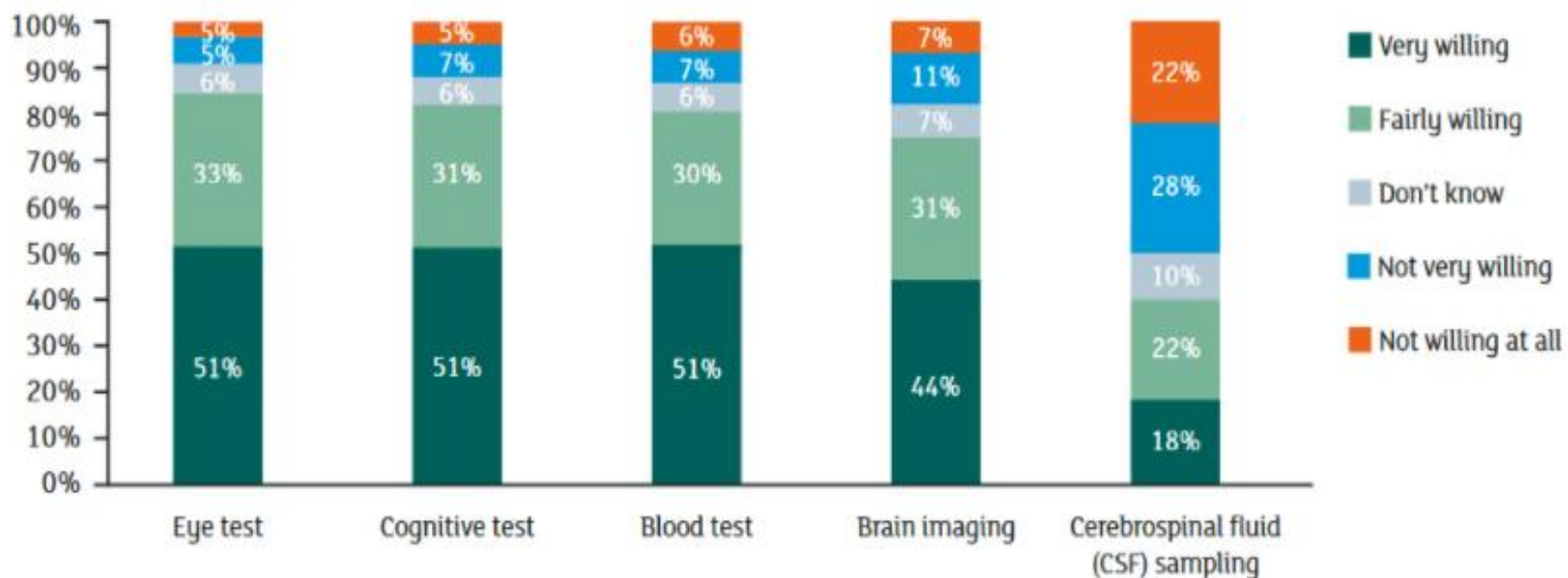


Figure 9: Early diagnosis of dementia survey, Populus (2019)

Every five years

after the age of 65 the risk of developing dementia doubles.

Alzheimer's Research UK

49%

Only 49% of people believed that Alzheimer's disease begins decades before any symptoms emerge, as current evidence suggests.

Source: Corrada, M et al (2010). Dementia Incidence Continues to Increase with Age in the Oldest Old The 90+ Study. Ann Neurol. 2010 Jan; 67(1): 114–121.

Alzheimer's Research UK

Epilepsy & Dementia



CATHY ADADEVOH

RM/RLD/BSC COMMUNITY SPECIALIST PRACTITIONER, MSC EPILEPTOLOGY

What is epilepsy?

- ▶ **A disorder of brain function.**
- ▶ Epilepsy is a **common neurological** condition that is defined as a tendency to have recurrent unprovoked seizures... (Panaytopoulos 2005).
- ▶ Investigations and diagnosis is normally made on 2 seizures*
- ▶ Not a disease
- ▶ You can't catch it from somebody else
- ▶ Approx. 1 in 10 people can have a seizure at any time in their lives. 87 people a day are diagnosed with epilepsy. 1:101 people have epilepsy in UK, 1:67 over 65yrs and 1:220 in children under 18 years. 1:5 with LD, Prevalence 600,000 in uk.

What is dementia?

- A general term used to describe a number of diseases that affect the brain that have similar symptom patterns
- Generally characterised by progressive decline in all areas of functioning
- The damage caused by all dementias leads to loss of brain tissue. This cannot be replaced so leads to symptom deterioration over time

Understanding dementia - theory

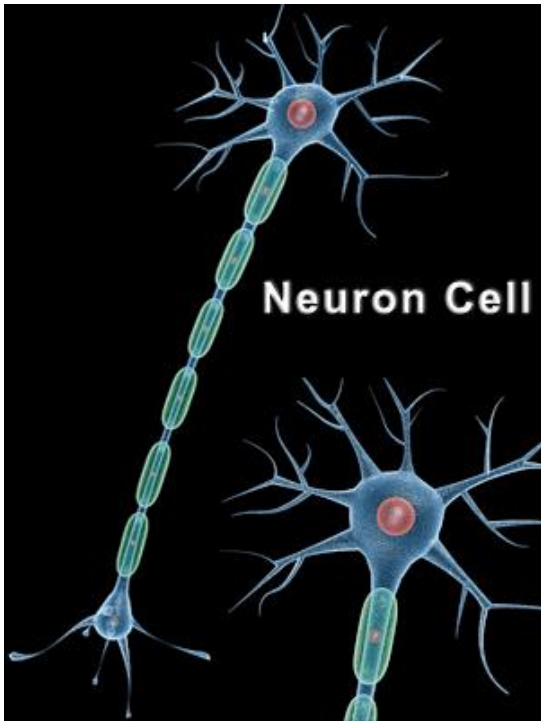
1) Law of Disturbed Encoding (Buijssen, 2005)

The person is no longer able to transfer information from their short term memory and store it in their long term memory. This means they are unlikely to remember things that have just happened to them.

Some consequences:

- Disorientation in an unfamiliar environment, or disorientation in time.
- Asks the same questions repeatedly and loses track of conversation.
- Less able to learn anything new including new people
- The person easily loses things
- May experience anxiety and stress

What is epilepsy?



- Anything that disturbs the normal pattern of neuron activity — from illness to
- brain damage to abnormal brain development — can lead to seizures.



- Normally develops in childhood
- Becoming common in later life

PHYSIOLOGY OF BRAIN

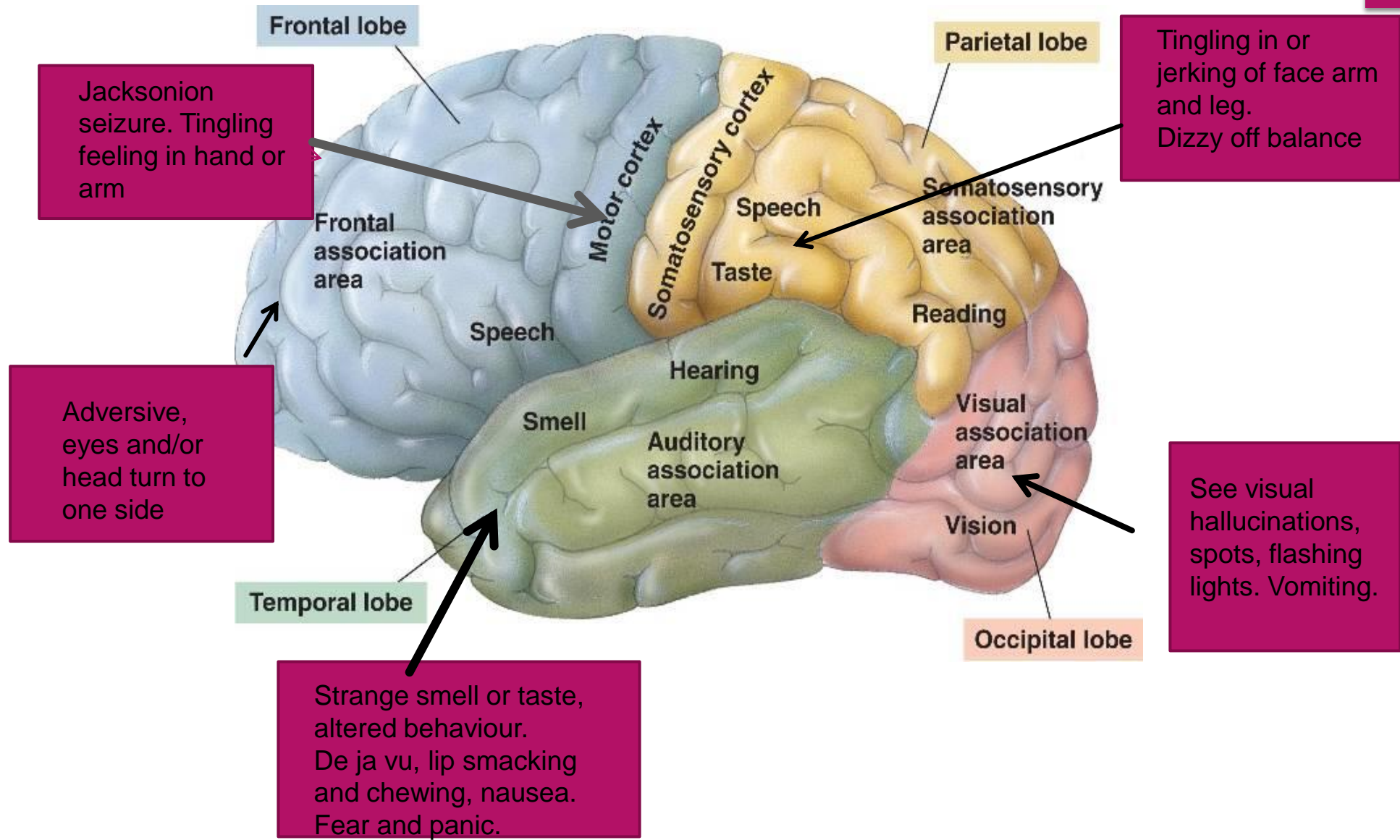
- ▶ **NEUROTRANSMITTERS** are the brain chemicals that communicate information throughout our brain and body. They relay signals between nerve cells, called “neurons.”
- ▶ The brain uses neurotransmitters to tell your heart to beat, your lungs to breathe, and your stomach to digest. They can also affect mood, sleep, concentration, weight, and can cause adverse symptoms when they are out of balance.
- ▶ Neurotransmitter levels can be depleted many ways. Stress, poor diet, neurotoxins, genetic predisposition, drugs (prescription and recreational), alcohol and caffeine usage can cause these levels to be out of optimal range.

SEIZURES

- ▶ Seizures happen when normal “cell to cell” communication process goes wrong or is faulty..
- ▶ It is a sudden onset of excessive nerve impulses either in part or the whole brain. This imbalance between brain cells manifests as a malfunction of these cells. Outwardly for example can be jerking or involuntarily moving etc...



**Neuronal networks tightly packed into Lobes and
Finely synchronised to perform routine functions.**

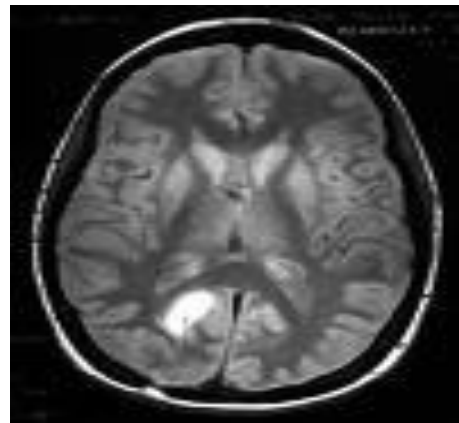


Symptomatic

- ▶ This is where there is a known cause for a person's epilepsy, such as a head injury, infections like meningitis, the brain not developing properly, a stroke, a scar or a tumour. A scan, such as Magnetic Resonance Imaging (MRI), may show the cause.

Clinical Manifestations:

- ▶ Frontal lobe seizures: manifest with prominent motor manifestations (tonic, clonic, or postural); show frequent complex gestural automatisms at onset;



Idiopathic

- ▶ Referring to a disorder of unknown cause.

This is when the epilepsy is likely to be due to a genetic tendency, inherited from either parent. Or from the abnormally produced genes in the persons early stages of development/in utero.

Onset usually infants-childhood-young adults.

DIAGNOSIS

- ▶ General physical examination by specialist
- ▶ Accurate history taking (of seizures)
- ▶ EEG (records brain/electrical activity)

- ▶ MRI (for tissues abnormalities)
- ▶ CT (for structural abnormalities)

- ▶ Blood tests (for imbalance or deficiencies)
- ▶ Observation of a seizure

Causes of Epilepsy - Physical

- ▶ Birth injury & brain malformation
- ▶ Tumour
- ▶ Scarring & Trauma
- ▶ Vascular (Stroke or Hypertension)
- ▶ Infection (Meningitis, encephalitis, syphilis)
- ▶ Other degenerative conditions



Causes of Epilepsy - Metabolic

- ▶ Lack of oxygen
- ▶ Low blood sugar
- ▶ Low blood calcium
- ▶ Electrolyte imbalance
- ▶ Water Intoxication
- ▶ Kidney or liver failure
- ▶ Drugs & poisoning
- ▶ Alcohol dependency
- ▶ Sudden withdrawal of other drugs



Causes of Epilepsy-Genetic Factors

- ▶ types of epilepsy have been traced to an abnormality in a specific gene
- ▶ defective genes for *ion channels*
- ▶ cystatin B. (gene missing in people with progressive myoclonus epilepsy)



Prevalence – How common is it?

- ▶ It is a cause of premature death for approx 500 people per year in the UK
- ▶ 20% of cases are difficult to treat

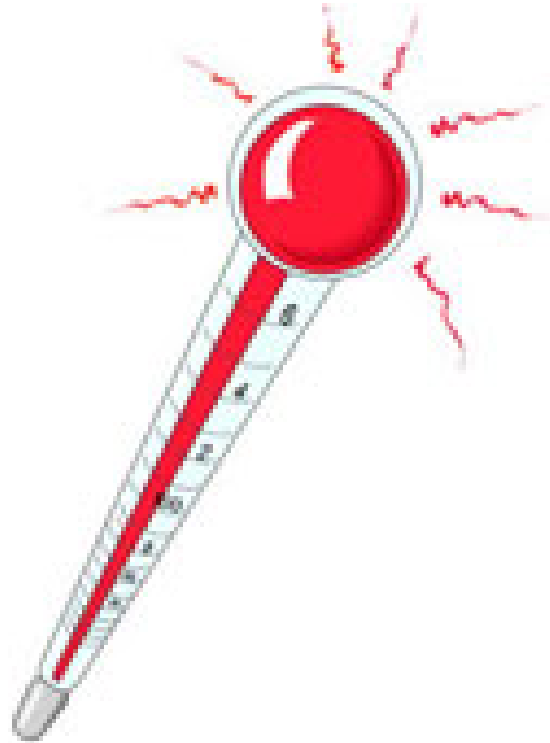
Psychological Triggers for Epileptic Seizures

- ▶ Stress
- ▶ Fatigue
- ▶ Anxiety
- ▶ Boredom
- ▶ Unhappiness



Physical Triggers for Epileptic Seizures

- ▶ Ill health
- ▶ Hormonal changes
- ▶ Constipation
- ▶ Changes in food consumption
- ▶ High temperature
- ▶ Alcohol or drugs
- ▶ Exposure to some aromatherapy oils.



Environmental Triggers for Epileptic Seizures

- ▶ Flashing lights
- ▶ TV
- ▶ Patterns of light and sounds
- ▶ Excessive heat or cold.



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info@decew.co.uk
events@decew.co.uk
chinno@decew.co.uk

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(CIC)

