



## CROYDON EPILEPSY SOCIETY

### NEWSLETTER

Winter 2018

We come to the end of another year with Christmas being heavily promoted in our shops and the media and we wish all our members a **Happy Christmas** and **Prosperous New Year**.

Brexit which I have not mentioned before is still in the balance but we can only hope by March 2019 that a final agreement is made between Britain and Europe.

The budget in November provided more help for those claiming **Universal Credit** with an extra £2.7 billion pounds and the deadline for full implementation has been extended. I know some of our members have been affected by this new allowance.

In our earlier Newsletters this year we have spoken about the restrictions on the use of medical cannabis being relaxed. However, a final decision about who can benefit by its use is still under discussion.

In the summer there was publicity in the media about **SUDEP** - sudden unexpected death in epilepsy. A family living in England was raising its awareness after their daughter Emily Sumaria, a 19-year-old girl university student died as a result of SUDEP. Her mother Rachel, Emily's father Bharat, her sister Amy, 27 and her boyfriend James Hewitt, went on a a marathon 6,000km in an **Indian** tuk tuk from London to Istanbul.



On the 11th November 2018 we remembered the 100th Anniversary of the ending of the 1st World War.



Dawn Gibbons, Honorary Secretary

## Universal Credit - Budget Update

The rollout of Universal Credit is being delayed once more, with a new target date of December 2023 for all claimants to be transferred to the Government's flagship new benefit. The announcement came as Chancellor Philip Hammond provided an additional £6.6 billion over the next six years to smooth the introduction of UC, which replaces a range of welfare payments. Mr Hammond revealed the Treasury would be giving £1bn over five years to the Department for Work and Pensions to help ease the transition to the controversial benefits system. He also said he was increasing the work allowance – the amount claimants can earn before Universal Credit begins to be withdrawn – by £1,000 a year, at a cost of £1.7bn annually.

## SUDEP - Sudden Unexpected Death in Epilepsy

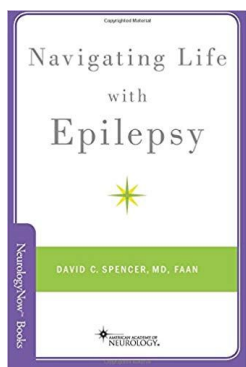
There are at least three epilepsy-related deaths a day in the UK.

**SUDEP Action** is dedicated to raising awareness of epilepsy risks and tackling epilepsy deaths including Sudden Unexpected Death in Epilepsy. They are the only UK charity specialised in supporting and involving people bereaved by epilepsy.

Sudden Unexpected Death in Epilepsy (SUDEP) is the term used when a person with epilepsy dies without warning and where the post-mortem fails to establish any other cause of death.

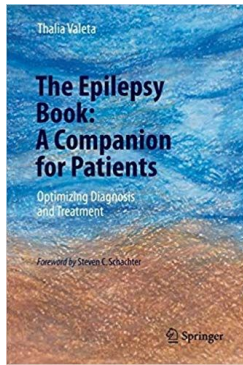
Their services include bereavement support, counselling, help with understanding the inquest process and in collaboration with UK research teams, the involvement of bereaved families and professionals in research through the Epilepsy Deaths Register. If you have been affected by an epilepsy death, please contact their support team on 01235 772852. Visit their web site <http://sudep.org>

## Books on Epilepsy



**Navigating Life with Epilepsy (Neurology Now Books) Paperback by David C Spencer**  
Published 1 Nov 2016 RRP £14.99

Navigating Life with Epilepsy aims to provide clear and reliable information about epilepsy, including "what" (definition), "how" (pathophysiology), "who" (epidemiology), and "why" (etiology). The volume guides the reader through current approaches to diagnosis (including a review of diagnostic tests) and treatment, and shares patient experiences and advice on navigating the myriad psychosocial challenges associated with epilepsy.



**The Epilepsy Book: A Companion for Patients: Optimizing Diagnosis and Treatment Hardcover by Thalia Valeta**  
Published 12 Dec 2017 RRP £9.99

This book presents scientific evidence about epilepsy along with straightforward guidance and recommendations. Responses to frequently asked questions and clarification of uncertainties are provided to empower patients to optimize their medical, psychological and social care. This book helps mediate between patients and health care professionals and can assist both sides to understand the condition of epilepsy at all levels.

## Christmas Events

Fairfield Halls shut in July 2016 for a major £30 million refurbishment. Croydon Council originally said the theatre would be up and running again in July 2018, two years after it closed, before the phased opening was pushed back to November 2018.

A cabinet report released ahead of a council meeting on March 19th, detailed the progress of the makeover and set a new, later date for a full opening by the end of March 2019. However, it is now re-scheduled for September 2019.



However, if you want to visit a pantomime this Christmas you can book “**Cinderella**” at Bromley Churchill Theatre. From Saturday 1st to Sunday 30th December.

<https://churchilltheatre.co.uk/Online/bromley-pantomime-panto-kent>

## Useful Information:

### Croydon Health Services Neurology Department:

If you are a local support group requesting more information on epilepsy and for a speaker to come to your group to talk about epilepsy and the support available to those who may have epilepsy or be a carer for someone who has the condition. Please email for general enquiries [ch-trspecialistmedicine1@nhs.net](mailto:ch-trspecialistmedicine1@nhs.net). The Neurology department includes providing support to those with epilepsy. There are two epilepsy nurses working in the department and they be able to visit your group and provide such a service.

**There is a Epilepsy Nurse Hotline/Advice telephone number which is open to GP's and patients (who are already known to the Epilepsy Service).If you are registered with a Croydon GP and under the care of a Croydon Neurologist and feel this service would benefit you please discuss with your GP who would be able to provide you with the number.**

**The Croydon Carers Support Centre** in George Street is open to provide support to carers.

**Croydon Age UK** offer a range of practical home services for everyone living in the local area, especially those in later life. These include : Handy person, Home Help, Trades Persons List and Nail Care. Charges do apply. Tel no: 0208 683 7120, email [homeservices@ageukcroydon.org.uk](mailto:homeservices@ageukcroydon.org.uk), [www.ageukcroydon.org.uk](http://www.ageukcroydon.org.uk)

## **Croydon Epilepsy Society Contact Details**

**Please contact us by phone or email.** Please leave a message on our mobile no or text us and we will get back to you asap.

**Further information can be provided by the following national support groups if you need urgent support:**

Epilepsy Action [www.epilepsy.org.uk](http://www.epilepsy.org.uk) Helpline 0808 800 5050  
Epilepsy Society [www.epilepsysociety.org.uk](http://www.epilepsysociety.org.uk) Helpline 01494 60140

Address: 64 Newlands Woods, Bardolph Avenue, Croydon CRO 9JR.  
Mobile No: 07926372711

Email Address: [croydonepilepsy@gmail.com](mailto:croydonepilepsy@gmail.com)

Visit our Facebook Page: [www.facebook.com/croydonepilepsysociety](http://www.facebook.com/croydonepilepsysociety)

Web Site: [www.croydonepilepsysociety.org](http://www.croydonepilepsysociety.org)

Twitter: Follow us @croydonepilepsy ( <https://twitter.com/croydonepilepsy> )

## **Elected Members**

### **President**

Professor F M C Besag, FRCP, FRCPsych, FRCPCH.

### **Vice - Presidents**

Yvonne Green

### **Honorary Vice - Presidents**

Dr P B C Fenwick  
Mrs Rosemary Aselford  
Mrs Rita Richmond

### **Committee Members**

Mr Marco Valencia Chairman  
Ms Dawn Gibbons Honorary Secretary  
Mr Richard Ruffell Honorary Treasurer

