The LDA Helpdesk Experience: 2012-2015

Dr Sandra Pearson, Medical Director, LDA
@PearsLDA

Personal details

- Medical Director: Lyme Disease Action since 2010. Academic and consultancy role
- Consultant Psychiatrist. Specialist Advisor CQC Mental Health
- Lived experience: Husband developed Lyme neuroborreliosis in 2008.

LDA Helpdesk

- June 2012: confidential email ticket system via secure server
- Operates 365 days/year including evenings
- Wide range of questions and queries
- 2 volunteers: establishing facts, giving information, refining questions
- Input from Medical Director
- 2669 #tickets
- 10 – 20 open tickets daily
- Medics helpdesk

LDA Helpdesk:The Context

- Patient focussed: High priority
- Improving diagnosis and treatment
- Evidence-based
- Ethical/Supportive
- Evolving: Service/Relationships
- Labour intensive
- Potential data for research
- How representative is it?

LDA Helpdesk:How it works

- Pre-test probability: Likelihood of Lyme disease?
- Who is involved in care?
- Testing via Reference laboratory
- Results: Authority confirmed with 2 forms of ID
- Data-mining, possible in-house interpretation?
- Discussion/Authorisation
- Communication in writing

Probability of Lyme disease?

Background history: Occupation, outdoor pursuits, medical history, medication

Tick exposure: Where do they live, ?Travel history

Tick bite: May go unnoticed

Erythema Migrans rash (EM): Only 65% notice the rash

Initial symptoms: First few weeks and months

Recent history: How are they now?

Lyme serology test results: ?Tested at RIPL, C6 EIA, Immunoblots, Lyme panel

Antibiotic treatment: For Lyme or any other condition ?Early inadequate antibiotics ?Immunosuppressed

LDA's view: Evidence-based approach/ Advocacy/ Communication

LDA Helpdesk: Initial Impressions

- Issues about medical awareness and knowledge
- Diagnosis relying on serology
- Effect of early insufficient antibiotics
- Issues with children
- Lack of specialists/ doctors with a special interest
- Importance of the doctor/patient relationship
- Medical ambivalence towards Lyme disease

Case study ?LNB/? Guillain-Barré

- 50 year old woman, long career as Police officer, about to retire
- Autumn 2012, Spring 2013: 2 Cycling holidays in Connecticut USA
- No known tick bite or EM rash
- 03/06/13: UK Hospital admission, bilateral facial palsy, sensory & motor peripheral neuropathy hands & feet (pain, paraesthesia, loss sensation, loss lower limb reflexes) LP1: 05/06/13 ?results
- 05/06/13 Local ELISA: Positive, diagnosed LNB by consultant > doxycycline 100mg twice daily 21 days
- Dramatic improvement in symptoms
- Neurology follow-up

Case study ?LNB/ ?Guillain-Barré Syndrome

- 'Confirmatory serology': Positive C6 EIA, negative immunoblots
- Neurologist diagnoses Guillain-Barré. Doxycycline stopped after 1 week
- Deterioration: unable to drive, difficulties walking due to pain and balance, marked weight loss, vomiting, joint pains, insomnia
- Contacts LDA helpdesk
- 04/07/13: Serology Positive C6 EIA, immunoblots negative
- 04/07/13 LP2 : CSF IgM +ve OspC (153), IgG negative with sub-threshold band. Raised protein.
- 08/07/13 GP Re-commences doxycycline –> improvement
- 11/07/13: Nerve conduction studies: Normal
- Sep 2013: Neurology OPA: Stops doxycycline–>Relapses. Buys walking stick.

Case study ?LNB/? Guillain-Barré

- 16/10/13: Serology repeated C6 positive, IgG Equivocal VlsE+
- 24/10/13: LP3: Normal protein, no WBCs
- 02/12/13: Case discussion RIPL
- 10/12/13: OPA Infectious diseases
- Jan 2014: Liaison between LDA/RIPL/ID/GP and local consultant: IV treatment authorised
- 15/01/14: IV ceftriaxone 2g/day, 21 days (IP -> OPAT)
- 02/02/14: 'Big improvement', corroborated by family
- 14/02/14: Relapse of symptoms
- 20/05/14: Second course of IV ceftriaxone -> sustained improvement
- 11/04/15: 'Really well'. Minimal residual symptoms. Corroborated by GP

LDA Helpdesk: Contact Details

- Available via LDA website: lymediseaseaction.org.uk
- Patients/Carers: support@lymediseaseaction.org.uk
- Healthcare professionals: medics@lymediseaseaction.org.uk