The Hidden Impact of Meningitis

Sue Davie, CEO
Who are we?

• Founders of the meningitis movement in the UK
• Longest established and largest meningitis charity in the world
• Our vision – where no-one loses their lives to meningitis and everyone affected gets the support they need to rebuild their lives
• Saving lives and rebuilding futures through:
  – Research
  – Awareness
  – Support
Meningitis – the disease

• Inflammation of the lining of the brain and spinal canal

• Caused by bacteria and viruses

• Under 5s are most at risk then adolescents

• Over last 10 years, average of over 3,000 bacterial and double that of viral meningitis each year

• Vaccines only exist for some forms of bacterial meningitis
Bacterial Meningitis – the impact

- 10% die
- We used to think that 10-15% left with after-effects
- Visible after-effects easily recognised e.g.
  - limb-loss
  - deafness
  - muscle weakness
  - cerebral palsy
  - severe brain damage

But what about the hidden impact?
MOSAIC Study

• Meningococcal Outcome Study in Adolescents and in Children

• Commissioned by Meningitis Trust to:
  o Measure physical, psychological, social, economic impact of MenB
  o Understand after care needs
  o Support the need for, and introduction of, a MenB vaccine

• Undertaken by UCL Institute of Child Health led by Professor Russell Viner and Dr Deborah Christie

• Funded by Meningitis Trust with support from The Big Lottery and Garfield Weston

• Only study done specifically on MenB – 221 matched case/control pairs, 573 children in total

• Findings published in Lancet Neurology in 2012
MOSAIC Findings

• **Cognitive Skills** - survivors significantly more likely to have
  - Borderline low IQ (verbal and non-verbal)
  - Deficits across all aspects of memory and sometimes in multiple aspects
  - Poorer executive function leading to problems with organisation and planning

• **Physical**
  - Significantly more likely to have epilepsy
  - 5 times more likely to have speech & communication issues
  - 5 times more likely to have hearing impairment

• **Mental health** – 1 in 5 children who survive have anxiety and behavioural disorders
Impact on children

- 1 in 3 children who survive have one or more problems with cognitive, physical or psychological function.
- As children get older, different issues become apparent such as executive function.
- Issues are frequently not linked back to the meningitis and children often just labelled as naughty.
- Frequently any assessments that are done are undertaken by professionals with limited knowledge of acquired brain injury.
- Children’s education suffers as they are not given the support they need affecting their long term future.
- Family relationships can break down.
Parents thoughts

**Emotional**
- Opportunity to talk to someone
- Psychological support…facing her mortality…problems with sleep…panicky with death

**Educational**
- Understanding needs

Someone to talk whilst everything is unravelling.

Might still want to be able to talk to someone about [child’s] meningitis as still affected by the shock now

Identifying his needs especially at school. Help and support with his education
Our Campaign

• Empowering parents
  o Providing the science (MOSAIC) to support what they already know to help them to be heard
  o Accompanying them in meetings with schools/teachers
  o Helping them to connect their child’s challenges at school back to the meningitis they experienced often years before – My Journal

• Educating policy makers/influencers

• Calling for appropriate educational assessments
  o Regularly through academic life
  o By professionals who understand about ABI

• Working in partnership with other organisations e.g. Training programme for SENCO’s/teachers with Child Brain Injury Trust
My Journal – empowering parents

• Keeping record of meningitis experience, appointments, medication, concerns, questions for professionals

• Downloadable factsheets including:
  o Structure and function of the brain
  o Physical effects of ABI - information on hydrocephalus, epilepsy, problems with movement and co-ordination, headaches, fatigue, appetite and weight change, incontinence
  o Sensory effects of ABI - information on hearing loss, sight loss and visual disturbance, touch, taste, smell
  o ABI Speech, language and communication problems
  o Learning and Cognitive effects of ABI
  o Emotional and behavioural effects of ABI caused by meningitis and septicaemia
  o Hearing loss and tinnitus

• Information on support
Life after meningitis

• They have already had to fight for their lives

• They should not have to fight for their future

Let’s fight together to give them the best chance possible for the future