“Vaccine cost system lets harm from meningitis B continue”

Emmeline McArdle, a nurse from Kent, knows only too well the devastation that meningococcal B meningitis (MenB) and septicemia cause. Her sister Jolene was just 19 when she woke in the early hours of the morning complaining of aching joints and flu-like symptoms. A little over 24 hours later, Jolene was dead, leaving behind a family that 12 years on still feel the loss.

MenB infection can kill a healthy child within hours of the first symptoms appearing and will leave one-third of survivors with life-altering after effects that can be as severe as brain damage, deafness and amputations.

A vaccine that protects against MenB was licensed in January 2013 but, in June of the same year, the UK’s Joint Committee on Vaccination and Immunisation, which makes recommendations on what vaccines the government should make available, said MenB vaccination was unlikely to be cost effective.

Our response as a charity that knows only too well the devastating personal consequences and wider costs of this disease was to highlight the areas we thought had been undervalued.

For example, the diversity of disabling after-effects are hard to capture and were not fully represented, nor were the wider health impacts on carers. Our full response can be read at www.meningitis.org/menb.

As the debate continues, it has become clear that, although it is important for all the relevant costs to be considered, it is the underlying methodology of the cost-effectiveness analysis (CEA) that is making it harder for vaccines that protect children against rare but severe illness to make the cut.

There is evidence that the public prefer preventive interventions over cures, and would rather prevent death or severe disability in a few than mild illness among the masses. However, CEA does not reflect these preferences. Children are at a disadvantage because much higher importance is placed on immediate health gains compared with those that are sustained far into the future.

To put this into context, CEA values the overall health loss associated with 5,400 cases of uncomplicated influenza to be the same as the death of a three-month-old child with an average UK life expectancy (80 years). Add to this the fact that the tool currently used cannot adequately measure health loss in children, then it seems that the MenB vaccine and future childhood vaccines for rare, severe illnesses will face an uphill struggle.

We submitted our reservations to the JCVI about the fairness of the cost-effectiveness model before they reconvened in February 2014.

While we wait for their decision, we continue our campaign for the introduction of safe and effective meningitis vaccines.

The Meningitis Research Foundation is backing a letter to the health secretary from doctors, nurses and scientists. Visit www.meningitis.org/menb to join us in the fight against meningitis.

Claire Wright is medical information officer, Meningitis Research Foundation

Don’t assume all want openness about dying

Not too long ago it was common not to tell patients they were nearing the end of their lives, particularly if health professionals or relatives felt a patient was too emotionally fragile to deal with this fact.

Today, palliative care policy and philosophy favour a more open approach, where all parties acknowledge that the patient’s death is approaching.

There are many benefits of this approach, but our research report on page 21 suggests it does not suit everyone.

Patients were often unaware they were nearing the end of their lives, despite having been informed of this – essentially, they chose not to hear.

The authors say there is no ideal way to discuss dying, and it should not be assumed that full awareness is right for all. They call for new ways of delivering palliative care so professionals can meet individual needs for information.

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