

# Child Death Prevention Newsletter

*This newsletter is designed to raise awareness and share the learning from the Child Death Overview Panel for Staffordshire and Stoke-on-Trent*

Issue 35 March 2018

Top tips for  
triaging  
& treating



kids with  
Down's  
Syndrome

Children with Down's syndrome (trisomy 21) are all unique individuals with their own personalities, family backgrounds and preferences that make them who they are. Most kids with Down's Syndrome have some physiological and behavioural differences that make it difficult to assess how sick they actually are.

**'Top tips for triaging and treating kids with Down's Syndrome' (overleaf)** tackles some of the issues seen in the under treatment of sepsis and is being promoted through the Down's Society and various facebook initiatives by Dr Herrieven, EM Consultant and proud mum of a wonderful daughter with Down's Syndrome.



[www.safeguardingchildren.stoke.gov.uk](http://www.safeguardingchildren.stoke.gov.uk)



**Most kids with Down's Syndrome (trisomy 21) have some physiological and behavioural differences that make it difficult to assess how sick they actually are.**



**1. Poor temp control:**

may not develop a fever at all, or may be hypothermic instead

**2. Weak immune system:**

Infections that usually cause only minor illnesses can be dangerous to kids with DS. Amy (in the photo below) spent a week ventilated in PICU when she had chicken pox!

**3. Mottle easily:**

Kids with DS have poor control of SVR, and get mottled ("corn beefy") with temperature change as well as sepsis, making assessment tricky.

**4. Co-morbidities common**

Remember cardiac problems, GORD, coeliac and autism (& don't forget the drug history)

**5. Leukaemia is more common**

and may present atypically

**Top tips for triaging & treating**



**kids with Down's Syndrome**

**6. Ask what's normal for this individual child**

Assessing levels of alertness, responsiveness, tone etc. can all be difficult if you don't know the individual child at baseline. Ask parents: they know their child best!

**7. Narrow tubes, thicker mucus**

Kids with DS get more chest & ear infections, and generally produce more snot!

**8. Explain and reassure**

Kids with DS often have sensory processing difficulties and can be very wary of new sensations: BP cuffs and sats probes may be terrifying. Take time to explain and reassure.

**9. Beware of atypical presentations of serious illness**

Sepsis can present atypically (as well as leukaemia, see #5) - e.g. chest infections/pneumonia with sepsis presenting as D&V



**10. Optimise communication strategies**

Speech & language development lags behind understanding, so kids with DS often understand more than they can express. They're often great visual learners (but have poor short-term auditory memory and fluctuating hearing loss) so use sign, pictures and gestures. Speak slowly, clearly and maintain eye contact. Allow for sensory processing delay of several seconds: don't hurry a reply

**Don't panic! Just don't forget the extra chromosome**



© Elizabeth Herleven - @Liz178 (EM consultant & mum of Amy) & Linda Dykes - @mmbangor

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