Feedback from the Tell it Right study day, Royal Bolton Hospital

Friday 22nd July 2011

35 completed evaluations.

What actions will you take following today's learning?

- Made me look at how I give information and how I can improve the experience for women and their families
- Going to look into the local support group – Bolton Smiley Faces
- Cascade information to the other staff on the ward (4)
- Pass on my gained knowledge from the day to my area of work
- Read more about Down's syndrome
- Discuss with colleagues the development of a care pathway and a central point for access of information in Neonatal Unit
- How to approach parents, the top tips of what to say, how to access the local support group
- Produce network of support available on the ward and a resources box of information for parents (3)
- Ensure that there are resources available on the postnatal ward regarding Down's syndrome especially the contact numbers for support groups
- Take more time to discuss AN screening with expectant parents and place some emphasis on the positive to balance the information
- Provide more written information and support group access
- Share information re support group in Bolton and give families more written information (3)
- Disseminate all the information I have gained to ALL staff on postnatal at Bolton
- Promote Bolton Smiley Faces (4)
- As a student midwife I found today educational making me think about the emotional support, guidance, information and local groups that I can offer to parents. Also to be thorough with AN screening discussions
- Ensure that I contact Smiley Faces when I have parents on the unit or in the community
- Ensure that clear, consistent information is discussed with expectant parents
- I am enthused but feel the need to undertake further learning to cascade and create best practice protocols

- Research more information to educate myself and surrounding colleagues
- Discuss with the relevant people about the information that is required to enable midwives to provide support and information to new parents of babies with Down's syndrome.
- I will check on the procedures for breaking news, support and information giving in my unit but am fairly confident that they will be up to standard
- Ensure that we have adequate, up to date information prior to telling parents of a diagnosis
- The need to improve communication and interaction between community and hospital services
- Liaise with screening midwife to check when AN diagnosis made that support, leaflets, contact numbers for Smiley Faces and DSA are all given to parents so that they can make informed choices
- To listen more – it's not all about a tick list of what we have to say (2)
- Really made me think about what parents need – I'll disseminate all the information to my colleagues in the community and get the Bolton Smiley Faces information into all Children's Centres in Bolton

What key messages strike you from today's learning?

- Listening to parents and allowing them the time they need to make decisions
- That the mum's feel that it has been an inspirational experience to have a child with Down's syndrome – wow
- Down's syndrome is not a really negative condition and there is some brilliant support available for families
- That Down's syndrome is not all BAD news
- Remember when giving information that all parents are different with different needs so ask them!
- As many positives as negatives – be balanced (4)
- Individual care for parents to enable them to see the potential of their child
- That people with Down's syndrome are individuals like anyone else
- Providing more individualised care to families. Anne-Marie was an inspiration and I would value her help and experience if ever required
- I have learned more about Down's syndrome today than I ever knew, all this information should be widely spread to let people know how fulfilling their lives can be

- That individuals with Down's syndrome can go on to live fulfilling, rich and rewarding lives (2)
- That screening in the antenatal period is of huge importance when providing fully informed choice making for women and their families
- Do not just bombard parents with predictions about what their baby may or may not do in life
- 1:1000 babies born – more common than I anticipated
- More understanding of what parents actually want from HCP's
- How we can easily fail people. Good communication, listening and supportive skills are necessary
- Introduce information in smaller doses and to ensure that only those with appropriate knowledge give the key information to expectant and new parents
- There are always choices but give families the accurate information (2)
- Mums reflections were very powerful, I have much more understanding
- Empathy and understanding of the emotions of new parents and ensure that they are referred for ongoing support – where to signpost people
- That there is still a lot of stigma and prejudice surrounding children with Down's syndrome – I'd lost sight of this
- Negative attitude of health care professionals
- The parents perspective and how I can change their experiences depending on my practice
- To be open and honest with parents and give a balanced view (4)
- Need for privacy and individuality when breaking news – ensure information and resources are available
- The poor 'counselling' service we give
- Lack of knowledge from health professionals, poor interpersonal skills = women not absorbing the information that we feel we give
- Individual care for parents to enable them to be able to see the potential of their child
- From now on to ensure every women I work with understands that whatever the outcomes / decisions, I as a professional value that baby

How would you describe the overall impact of today's learning on you personally? Any other comments?

- Massive personal impact, particularly affected by hearing Anne-Marie's story but really uplifted by Ailsa and will take positive message back to my work area and change my practice

- Amazing study day. Ailsa is fantastic. I feel I can be much better equipped to support women ante and postnatally
- Very informative and enlightening (2)
- Learnt a lot of information
- Very moving
- Gave a balanced and more positive outlook of the condition
- Amazing! Moving, emotional and informative
- Very powerful, learnt so much. Many thanks
- Much more aware of people's feelings and emotions around the diagnosis of Down's syndrome
- Inspired by inspirational people (2)
- Very positive impact - learnt a lot (2)
- Brilliant, empowering, inspiring, tearful! (3)
- I feel humbled and overwhelmed by the positive impact that this day has had on my understanding and clinical practice. I feel much more informed and prepared for helping families with such outcomes
- More informed in general and learned how inspiring the families and those that have Down's syndrome are
- Absolutely brill day
- Empowering, practice changing, need to share this information
- Good consolidation and expansion of my previous knowledge. Emotional at times but I really responded with the mum
- Great information and skills that can be used daily – inspirational
- So much more aware (2)
- A really positive influence – will definitely affect how I support people
- Immense – for my future career, having the knowledge about how new parents feel and came to terms with the news will really help me provide care and support
- This has been an excellent study day
- Invaluable – wish I had been fortunate to have undertaken this study day years ago!
- Exceptional insights from the parents and Ailsa
- I feel empowered to pass on this information to other families and it has changed the way in which I will care for families. I have met some truly inspirational people today

Any other comments?

- Excellent study day. Ailsa is fabulous!
- A very enjoyable, informative day. Thank you! (3)

- I enjoyed the day immensely and learned an awful lot (2)
- Good day, very informative and positive
- One of the most valuable and informative study days I have been to
- All speakers were super
- All the speakers have been excellent
- I would recommend that this study day should be repeated to reach more people. This is the most inspirational study day I have ever attended
- Anne-Marie's story was both heart-wrenching and heart-warming. It showed all the pitfalls of postnatal care on a busy ward but ultimately that family life has just begun with this new baby and they are looking forward to the future. I wish them all well
- Very good to hear Ailsa and the parents experiences
- Hearing the parent's telling their experiences is a very real way of helping HCP's see how they can improve their care
- Key speakers were excellent and Ailsa was inspirational. Very well lead (2)
- Talk at the RCM conference and university to talk to student midwives
- Excellent Trainer – good interaction from the audience
- Insightful and informative, feel more equipped to share information with others – thank you
- So good to hear about the group, meet parents, Natalie and Ailsa – you were all brilliant
- This session was fantastic – I greatly appreciate gaining first hand experiences and feedback from the women – only from this can services be improved and adapted for the better
- Excellent study day that should be a regular and widespread training day for all health professionals (2)
- Brilliant day, good links with local support group made and excellent speakers (2)
- Study day should be part of our statutory study days
- Ailsa should be bottled and sold – what an inspiration
- Ailsa is brilliant
- Very useful and informative – will recommend this study day to colleagues
- Loved it
- A very well presented and professional study day, interesting speakers giving a huge insight into life with Down's syndrome
- Fantastic informative day. Message needs to get out to more people especially in the hospitals. Need to go into university to speak to the student midwives who are currently training

Any constructive criticisms?

- More time discussing issues rather than the results of the survey which were interesting but could have been summarised
- Lecture theatre too cold at times
- None – perhaps provide tissues! (2) only joking – was fabulous
- More open discussions – these were great!
- More of the same!

Ratings 1 – 5 of overall experience (1 lowest – 5 highest)

4 (3 people)

5 (31 people)

5+ (1 person)!

Trainer comments

This study day was dynamic and interactive from the outset, the delegates were engaged and involved and keen to share their experiences throughout the whole day. The honesty and integrity of the delegates and their obvious eagerness to understand more about Down's syndrome and how best to support women was very apparent and will, I am sure, lead to excellent practice.

There was a great deal of participation and it was wonderful to see the exchanges between the professionals and the local parents and support group. I am extremely confident that very strong links have been forged between Maternity Services and Bolton Smiley Faces.

As ever I was overwhelmed by the willingness of Anne-Marie, Jacqui, Natalie and Ailsa to stand and share their experiences, they were 'inspirational' and I am incredibly grateful to them all for making the day such a powerful experience for everyone. Thank you all

My thanks to Louise Speakman for her help and to Christine Jordan for her excellent presentation. What a great day!

Lou Marsden
Training Officer
Down's Syndrome Association
27.7.2011