NHS
Leeds
Clinical Commissioning Group

1. Background

The Maternity Strategy for Leeds 2015-2020 was developed based on extensive consultation with women and families in Leeds, using a detailed health needs assessment and the latest and best evidence of what works well in maternity services, taking into consideration national and local drivers. The strategy outlines 9 priorities which aim to improve maternity services by providing safe, high quality maternity care, meeting the needs of all families in the city.

As part of the targeted support project, work has already been completed to improve services for women and partners using maternity services who have learning difficulties, perinatal mental health and work is ongoing around improving the service for young parents and homebirth. This piece of work is focusing on improving the bereavement care pathway.

2. The Engagement

The engagement is building on ongoing improvement work which has been delivered in partnership with service users. In January over 60 people attended a workshop for both professionals and service users using the “Whose Shoes” tool to look at bereavement care across the care pathway and identifying further improvements to be made.

3. The ‘Whose Shoes’ workshop

‘Whose Shoes’ is a board game which helps people understand and engage with the maternity personalisation agenda. It helps participants work across boundaries and co-produce imaginative, local solutions to work together for excellence, always with the person in the centre. This tool enabled the players to use the scenarios and topics to explore concerns, challenges and opportunities within the service in Leeds. The workshop was aimed at families who had experienced miscarriage or bereavement in pregnancy or postnatally and for professionals who support these pathways.

We were keen to find out about people’s experiences and to have a safe space for people to share stories and have conversations. At the end of the workshop people were asked to capture three personal pledges on postcards provided. Each table were asked to share one or two pledges with the rest of the group. Quotes taken from post it notes from each table are captured in Appendix A.

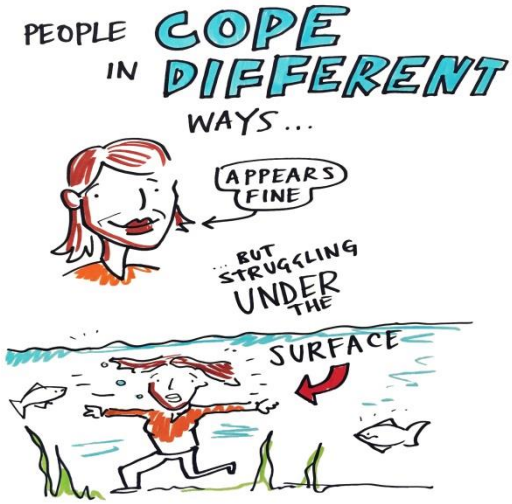
4. Themes

Tom Bailey, artist, attended the event to draw the stories people were sharing: below are some of the themes people felt were important

a. staff and patients need to know what support is available

b. choice

c. people cope differently



d. don’t forget family and dad

e. Giving Birth

f. honesty

g. hospital visit

h. How we want to be treated

i. I know how you feel????

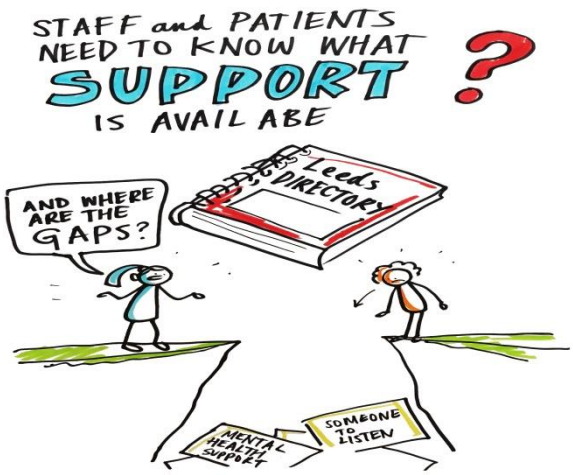
j. meeting my midwife is important

k. we don't want to re-tell our story

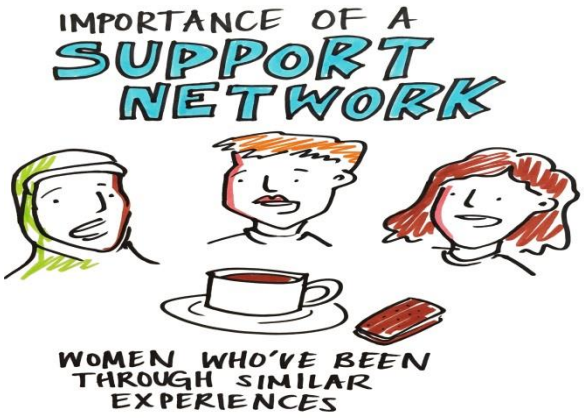
l. sibling support is important

m. staff need support too

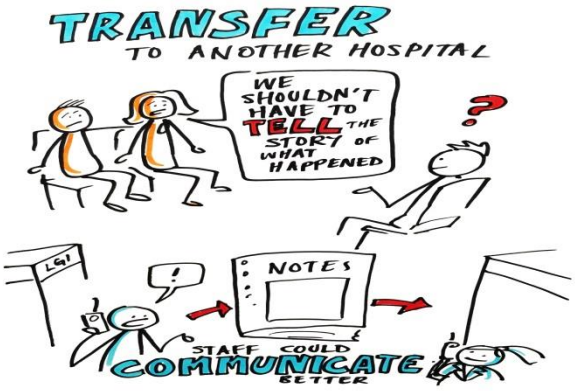
n. information on support available is crucial



o. peer support network is important



p. better communication between hospitals



5. What happens next

In addition to the workshop, there is also a bereavement survey which is currently live for people to complete. Further meetings are being planned to discuss next steps

Helen Butters

3 April 2018

Appendix A

Maternity Bereavement workshop post it notes quotes from the tables

- Personalisation when explaining things
- Don't use language that is bound to heighten anxiety
- Some information needs to be given but anxiety should not be raised unnecessarily
- Simple explanations – drawings help
- Grief and bereavement are not time limited
- Acknowledging friends bereavement different ways of helping friends – is this person getting the right support
- Understanding stages of grief
- Should have mandatory training for al student midwives and voluntary sector professionals
- Professionals being open and sensitive to patients need
- Staff worry about the aftermath – if emotions are not shown / known
- The loss of a 40 week pregnancy – opportunities / hopes / dreams
- Parents can appear really brave at a time of loss separation – what's going on underneath?
- Transparency is so important
- Parents should receive information repetitively
- We can / will say the wrong thing…. Need to be sensitive to the response
- Reactions to loss are all so different – anger / silence / chaos
- Make sure car parking is sorted – put it on admission checklist
- In Leeds I was offered lots of choices during birth
- Light hearted but also serious – supportive
- Record conversations for bad news – mixed feelings on this – to explore further
- Self-awareness – how we react / respond / communicate – how this may be perceived by the other person / patient
- Transparency and openness of staff explaining why we scan – this may partially prepare parents that this is under investigation
- Ways of breaking bad news – honesty and sensitivity and language used
- Put information about how to access support services for bereavement / miscarriage in with initial pregnancy information
- Use MVPs and text messages to get more informal feedback for families
- Poor aftercare – can cause huge issues after event
- Follow-up – after traumatic / difficult situations to show we care and not just deliver bad news
- Aftercare – lack of communication between staff – unaware of situation
- No aftercare - just left on my own – no support
- Re-open wounds – then left

- What happens after support ends? All services time limited
- Didn't get told what to bring to give birth – they don't prepare you in the same way as they do for a live birth
- Compassion and understanding. - to understand the patients journey
- Need to look after and appreciate services
- Lack of resources / services increase stress for staff / patients
- Feedback from Dads can be the most useful – they notice it all
- If you have lost a baby, how do you have any children
- If I don't think about it – I get on
- Need to stop women retelling her story
- "Pass on information tool" for staff and other hospital staff. An alert tool (info about the woman)
- Professionals need to keep re-iterating how people get back into support services
- Getting information from other parents is better than just from professionals
- No mental health support
- Provision of information and ensuring that the information is understood
- Flexible approach and ability to adapt our approach and / or language depending on context and our knowledge of patient and their history
- Staff support – needed for reflective space – supervision etc
- Expectations have never been so high
- Specialist teams – really good – but do they dilute 'normal' birth resource
- Staff resilience affects behaviours
- Self awareness as a professional
- Neo-natal units /ICU'scary place'
- How do we make staff feel valued? (now no clinical supervision)
- Need to support midwives so they can support women
- Improvements / extra resource antenataly has meant post-natal offering has been reduced
- Reconfiguration – have solution focused meetings with the team. Ask staff how are you. De-brief time. Supervision.
- Annual awards / staff nominations. Celebrate what doing well.
- Team building
- Supervision / clinical
- Helpline / Mindful manager
- Supporting professionals to adapt the changing roles and cultures of what is best for women
- Development – need to support professionals
- Its not just a job – support for staff – emotions
- Women need choice they are all individuals.
- We need to listen to their needs and wants – one size does not fit all.
- I know how you feel – no you don't. Every experience is different

- No-one took time to read notes – heightened stress
- Recording conversations – great idea in order to go back to retrieve key information – Don't repeat yourself
- How do staff switch off? – talk to each other Team support
- Team support – opportunity to chat
- Remove stigma – not doing my job properly
- Coping strategies – Helpline – taking personal time out ??exercise stress busting strategies
- Peer to peer support – safe space
- Parents could provide constructive feedback. NNU t ask for friends and feedback / audit
- HV needs to change. Does not have responsibility.
- Should treat all as individuals to make informed choices.
- Indirect approach, suggesting empowering women to make decisions
- People feel ashamed to access support
- Having someone else who has had similar experience to talk was the best support.
- Signposting to community services is vital for ongoing support.
- Someone to be there and listen.
- Language / jargon (causes confusion)
- Language really important
- Mind your language
- Cold medical language – not person centred
- o-body took responsibility to provide the women with information on how to access bereavement counselling
- Dads should be given choice to be given hospital accommodation – not going to be huge numbers
- Important for baby to stay close to mum if she is ill
- Should allow baby and dad to stay if mum is ill
- Continuity of carer before and after is essential for staff and families
- Informed consent – how do we assess content and timing? It's complicated
- What support is there for Radiologists?
- We need to (and are) listen actively and co-produce service improvement
- Do we provide enough opportunity for debrief and explanation if families are turning to social media to report experiences?
- Free speech. Criticised for sharing on social media. Shouldn't police people's social media. Should be allowed to be honest about their experiences. Closed groups can be helpful.
- Appy days – app to allow children to see what happens in hospital before admission. How can develop internet and intranet pages.
- Interpreting language in the Trust. Focus on baby not foetal loss. Think about the language used and always used compassion.

- Joining this up (yellow). Important to get the right help at the right time – if not this has huge implications.
- ‘Jargon’ pre term birth. Different use of language in health care for legality reasons but for general language think about the words used.
- Funeral service is very important offer.
- Lifeline – GPs as lifeline. Signpost to GPs who can refer to other services such as counselling. GPs need to be sympathetic.
- Have a Dad facility with toilets and showers etc.
- Have male peer support and role models.
- Professional resilience – valuing and recognising other people’s strengths and not being too hard on yourself. Self-care both personal and spiritual.
- Friends can feel they are walking on eggshells and avoidance of difficult conversations.
- A touch demonstrates that you care.
- Silence is powerful but hard to cope with for some.
- People want to share experiences and help services improve.
- Interpreter (green). Family and friends should not interpreter – for lots of reasons – hospital should ensure professional interpreter is present.
- Bereavement affects the whole family and so need to be mindful of that.
- Not late miscarriage – early labour, lost baby, baby born sleeping are terms that would be more favourable.
- Ward/private room to recognise loss no matter what age the baby is.
- Catch best practice between departments and shout about it! Positive relationships between departments.
- Different gestation time frames. Where best to put a lady based on gestation. Don’t involve patient in disputes in between departments.
- Bad experience – offer to come back and discuss is not always accepted and sometime put on a waiting list.
- Secret sorrow. Depends on context and who is asking. Don’t shut down my feelings. Be a good listener. Acknowledge my feelings with sensibility and do not make bereavement a taboo. Act appropriately to the response you receive.
- Early losses before 14 weeks should be recognised as a loss.
- Waiting for confirmation must be agony of abnormality.
- By not announcing before 3 months we are shaming ourselves if we miscarry.
- How do patient stories change practice?
- Unaware of campaign – needs to be promoted.
- We need more service users on stillbirth review panels. Service user sub group of bereavement group required.
- Acknowledge loss is important – that there was a baby as all parents have hopes and wishes.
- If you don’t have anything nice to say, don’t say anything at all.

- Overseas experience rapidly involved. Stillbirth mortality meeting every month. Risk management. National reporting and peer review – there is no reason.
- Rapid resolution scheme – compensation how is that going through the processes quickly. Learning from overseas experience rapidly. How can involve parents feeding into investigations.
- Early pregnancy – bouncing from service to service. Delay in communicating loss from EPU.
- We all want awareness.
- Showing emotion is healthy and demonstrated care.
- Individual not a number – patient centred.
- Limited support – self referral has a long waiting list.
- Pressure of targets causes conflict of interest.
- It still hurts even now.
- Not the time to be making jokes! Be careful with language. Remember to take time to understand their journey.
- Women feel guilty and responsible for the loss.
- We can't sweep negative experiences under the rug.
- How do you quantify loss? Is an early miscarriage less painful emotionally than a late miscarriage?
- When u/s shows something concerning could we have a call button for discreet help.
- Honesty is the best policy when something is wrong with the baby.
- Guilty around getting bored. Complete change of world. Lack of control and can cause anxiety in future years.
- Need better emotional support/counselling for miscarriage/stillbirth/neonatal death.
- How do parents tell children/grandparents that a baby has died?
- Patient stories.
- In case of an adverse outcome – invite parents to contribute to any investigation.
- Group support for bereaved siblings?
- Sibling support there is a gap as to what is available
- Clarity about why we are doing scans and get consent for each scan
- How could we do joint follow up appointments with more than one hospital
- Verbal handover of history
- Historical summery that is given to mother to take with her
- More detail about previous pregnancies and births
- Exposure to language re low lying placenta – you are a walking time bomb. Anxiety provoking. Need appropriate level of explanation. Requires compassion and empathy regardless of situation.
- Insensitive robotic language.

- People deal with things in different ways
- Flexible support that is patient focussed.
- Support network and people to talk to.
- Staff need to know what bereavement services are available as by not verifying this could have a huge impact on the woman.