

Disabilities and Pregnancy

Jenny Butters
Matron
Liverpool Women's Hospital

Carmel Doyle
Enhanced Midwife
Liverpool Women's Hospital



Liverpool Womens Hospital



Background:-

- Largest Maternity Unit in Europe
- 2016-2017= 8450 births
- Employ 300 midwives
- 40 maternity support workers
- 1 Consultant Midwife
- 13 Obstetricians
- Achieved UNICEF New Standards Stage 3



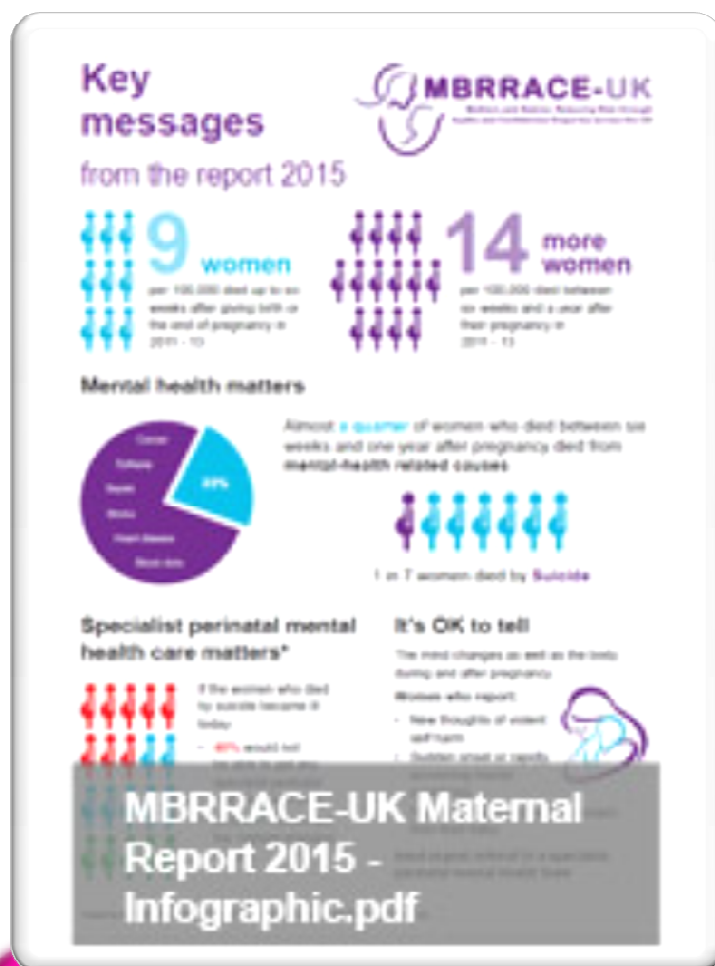
Aims of Session

- Awareness of how physical disabilities can impact on women in the perinatal period.
- Understanding of how Midwives can support women during this period.
- Awareness of how Midwives and Obstetricians can support and work together so that women can make informed choices during their pregnancy.

Aims of Session

- The importance of Multi-Disciplinary Teams in the co-ordination of care for Women with disabilities.
- The importance of Enhanced Midwifery in supporting Women with disabilities.

Drivers for improved maternity care



What is a Disability?

A disability is defined as:

‘ A disability is a physical, sensory or mental impairment that has substantial and long term negative effect on the ability to do normal daily activities.’

Equality Act, Secretary of State, 2010

Equality Act 2010

- Sensory impairments, such as those affecting sight and hearing.
- Impairments with recurring effects such as Rheumatoid Arthritis, Myalgic Encephalitis (ME), Chronic Fatigue Syndrome (CFS), Fibromyalgia, Depression and Epilepsy.
- Progressive such as Motor Neurone disease and Muscular Dystrophy .
- Auto- immune conditions such as Systemic Lupus Erythematosus.
- Organ specific:- Asthma, Cardiovascular disease, Thrombosis and Stroke
- Blind or Partially Sighted
- HIV OR MS

Barriers for People With A Disability

- Separation and segregation.
- Stereotyping
- Labelling
- Prejudice
- Barriers to communication.
- Inaccessible environments
- Attitudes and behaviours of professionals



What we can do.

- Midwives as lead professional's are pivotal in meeting the need of the disabled pregnant woman. Intervention at the earliest stage of pregnancy is crucial for a positive birth experience future parenting.
- Midwives are key to being the advocate for the woman and ensuring that physical access and professional attitudes do not prevent access or restrict choice to services but become the co-ordinator of the care provided.
- Providing choice, control and empowerment to the woman will enhance her pregnancy journey.

(Changing Childbirth,DOH,1993).



Model Of Care

- Two main models the medical model and the social model.
- **Medical model** defines disability from a non disabled person concentrating on the activities that they can't do which are seen as 'normal'.
- **Social Model**:- has two perspectives
 1. impairment is seen as the functional limitation of the body or of learning.
 2. Disability is seen as the structural restrictions or barriers caused by society which excludes them from main stream activities.

We have a Responsibility

- Health care providers have a responsibility regardless of ability to respect people as equal members of society.
- Midwives in England have a responsibility to understand how the NMC Code of Conduct, 2015 and Standards relate to supporting women with a disability.
- Be prepared to challenge personal views and be an advocate for the disabled pregnant woman.
- Disabled women may feel that they are being judged and not good enough to parent effectively.

We have a Responsibility

- Recognise the two models of care and instead of applying the medical model which concentrates on the disability but ask them what barriers stop them accessing services (e.g. stairs, poorly lit rooms, intercom services and information provided in an appropriate format.
- Understand about the laws of treatment who can give consent and for what.
- Have knowledge of local pathways guidelines or even more importantly work collaboratively to form new pathways!
- Use resources effectively to meet the needs, provide innovative midwifery care, providing woman centred care and providing choice.

Impact of Disability on Pregnancy

- Weight gain and mobility may be affected.
- Vulnerable, negative feelings of being in a hospital especially if they have had a previous poor experience.
- Fearful about the birth process and whether to have a vaginal or c/section.
- If women have sensory impairments worries about communicating.
- Women should be able to have a advocate/interpreter to support them in their communication.

Should We Consider Mental Health?

1

Developmental

Autistic Spectrum
Disorders (ASD)
Dyslexia
Dyspraxia XIA.

2

Learning Disabilities

3

Mental Health Conditions

Anxiety
Panic Attacks
Phobias
Eating Disorder's
Personality
Disorders
PTSD
Self Harm

4

Mental Illnesses

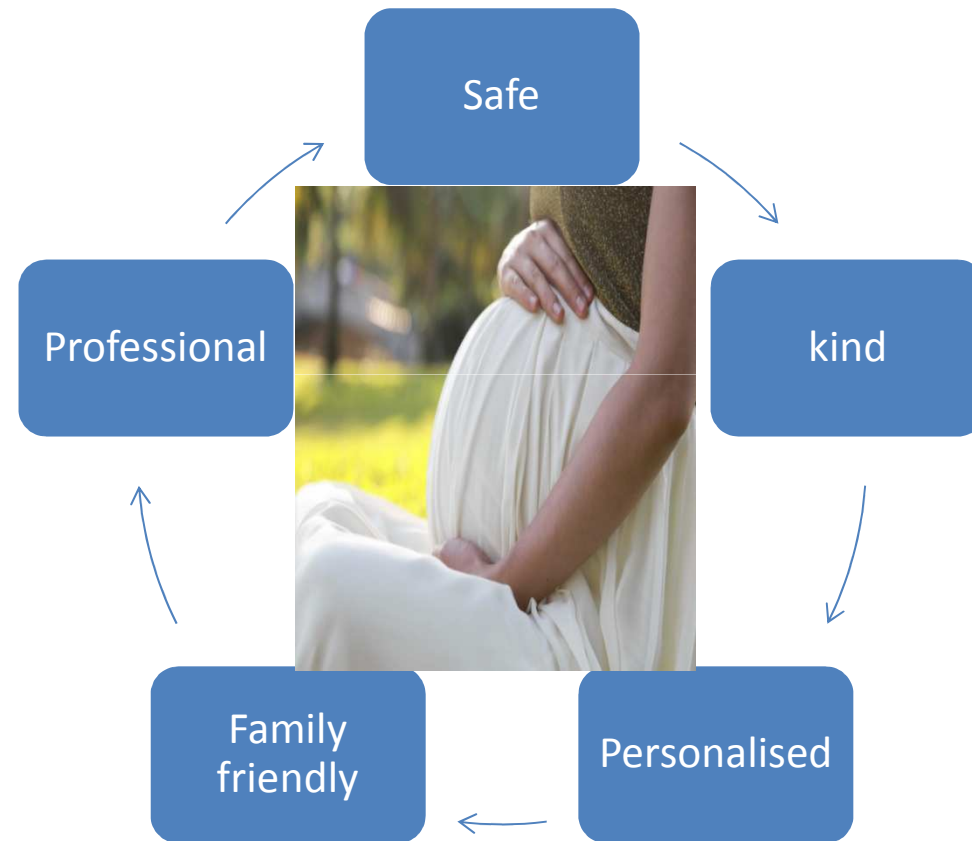
Depression
Schizophrenia

National Maternity Review 2017

“Our Vision for Maternity Services across England is for them to become Safer, More Personalised, Kinder, Professional and Family Friendly. Where every Woman has access to information to enable her to make decisions about her care and where she and her baby can access support that is centred around individual needs and circumstances.”

Dame Baroness Cumberlege, 2017.

National Maternity Review 2017



Worries for Women with a Disability

- Will I be able to carry my baby to term?
- Will I be able to undergo labour and deliver my baby safely?
- Will I be able to care for my baby and be a good enough mother despite my disability?
- Will services deem me as not good enough and remove my baby?

Disabilities in the Antenatal Period

- Women with a disability are referred to our early access maternity centre where they are booked for maternity care at a venue of their choosing/ safe place :-

Venues include:-

- Liverpool Women's Hospital Community Antenatal HUBS
- Hospital setting at Liverpool Women's Hospital
- Children's Centres
- Home

Antenatal Care and Physical Disability.

- Woman would receive care which adheres to the 'NICE Maternity Guidelines', 2014
- At each appointment the midwife would risk assess the woman and discuss how the growing uterus and her baby can impact on her; physically AND emotionally.
- Depending on their disability, women would be referred to a Consultant to review her care and to discuss mode of delivery and support which can be offered within the hospital setting/home setting.
- Her wishes will **always** be considered at each stage of her maternity.

Antenatal Care and Disability

- Refer as early as possible to the specialist or enhanced midwife for one to one midwifery care.
- Highlight a woman's strengths and concentrate on what they can do – social model of care, not what they can't do!
- Perform risk assessment regularly
- Communicate with Multi-Disciplinary Teams for women with complex needs.
- Parents should be encouraged to bring into hospital aids which support them during their hospital stay.

NICE Guidelines, 2014

At the first contact with a Healthcare Professional:-

- Folic Acid supplementation is discussed
- Food Hygiene, including how to reduce the risk of a food-acquired infection
- Lifestyle Advice, including smoking cessation, and the implications of recreational drug use and alcohol consumption in pregnancy
- All antenatal screening, including screening for haemoglobinopathies, the anomaly scan and screening for Down's syndrome, as well as risks and benefits of the screening tests

NICE Guidelines, 2014

- How the baby develops during pregnancy
- Nutrition and diet, including vitamin D supplementation for women at risk of vitamin D deficiency, and details of the [Healthy Start programme](#)
- Exercise, including pelvic floor exercises
- Place of birth

Risk Assessment Completed By Midwife

Liverpool Women's NHS Foundation Trust

HANDLING ASSESSMENT FORM

Physical, Sensory, Mental Health or Learning Disability

ID Label

Referred to Disability Advisor: YES/NO

Cultural, Religious, language considerations

Height Weight BMI

Mobility (comment below)	Date								
	Time								
Fully mobile	0								
Minimal assistance needed	1								
Requires use of walking aid, crutch, stick, Zimmer	2								
Requires assistance with gait	3								
Requires use of wheelchair	4								
Restricted to Bed	5								
Factors affecting mobility/handling (comment below)									
Confused or reduced level of communication/understanding	1								
BMI <20 or >30	2								
Skin lesions/wound/tissue viability	2								
Pain	3								
Vertigo, poor balance	4								
Mobility affected by medical sedation/spinal/epidural	5								
Other Limitations (comment below)									
Partially aligned	1								
Hard of hearing	1								
Blind	2								
Deaf	2								
Environment (comment below)									
Restricted environment e.g. confined space, steps, flooring, etc.	2								
Attachment restrictions e.g. IV, PCA, catheter, monitor, etc.	2								
Total score									
Assessor's signature									
Score 0-4	LOW RISK	Safe when using good handling practices, e.g. women with low BMI, good mobility, good comprehension, low level of handling constraints.							
Score 5-9	MEDIUM RISK	Caution, women who have specific needs and must be handled in a certain manner. Check care plan and comments below. e.g. women with pressure sores are not to be transferred via sliding.							
Score 10+	HIGH RISK	Stop! Do not manually handle, e.g. with a high BMI (>30), high level of disability or immobility, poor comprehension, or handling constraints. Check care plan and comments below.							
Comments									

This tool aims to assist staff in the assessment of women's mobility and handling needs. The Patient Handling Assessment must be completed on all women at 'Booking in' appointment and reviewed if there is a change in their mobility or handling needs. A score(s) is given in each section & the scores added up. The total score indicates which risk category the woman falls into, Low, Medium or High risk.

7

Enhanced Midwifery Role

- Women with a disability are offered one to one midwifery care from 16 weeks gestation.
- Women are provided extra visits (at home, children's centres or a venue of choice)
- A co-ordinated approach of care is provided.
- Enhanced midwife's work collaboratively with agencies to enhance the pregnancy journey of women who require extra support.

Enhanced Midwifery Criteria

- Mental Health Issues
- Teenagers
- Disabilities
- Learning Difficulties
- Asylum Seekers
- Early Intervention And Safeguarding
- Substance Misuse



Emotional Wellbeing and Disability

‘Evidence about early brain development has highlighted the importance of building a bond with the unborn baby’

RCM, 2017

Effect of Stress in the Antenatal Period

Recent evidence indicates that stress and anxiety in pregnancy can have harmful effects that may continue throughout the infant's lifespan (Mueller and Bale 2008; Talge et al 2007), although this may be influenced by its timing, magnitude and/or chronicity (Misri et al 2004; DiPietro et al 2006).



Persistently high levels of stress hormones such as cortisol, are known to have damaging effects on the development of neural pathways in the fetal brain (Glover and O'Connor 2002). Two primary systems that mediate the influence of women's moods during pregnancy are the autonomic nervous system and endocrine system (e.g. Hypothalamic Pituitary Adrenal Axis).

What can Midwives do during the antenatal period to support Women with a disability?

- If the woman's mood has changed they would complete a assessment and refer to their GP or a Specialist Perinatal Mental Health Team (Liverpool Women's Hospital).
- Refer women to the local psychological service to support the mother and baby relationship in the Perinatal Period .
- Offer choice and allow disabled women the chance to be the lead in their maternity journey. Therefore empowering them for their next pregnancy.

Cost Benefits of Having an Enhanced Midwifery Team

Cost Benefit Analysis: -

A Woman who was under the care of an Enhanced Midwife, had severe mental health issues, she had made numerous suicide attempts and would self harm, she had a disability and was previously in foster care as a child.

She costs the NHS and Local Authority per year £165,361.

One Enhanced Midwife costs the NHS per year £34,000 - £37,000.

(PSSRU UNIT COSTS FOR HEALTH AND SOCIAL CARE, 2016)

Savings of Early Intervention

- Early intervention and working in collaboration other agencies helps women become empowered and be able to make informed choices and stop escalation.
- Early intervention may reduce the Local Authority from intervening and removing babies into social care.
- Provide a foundation for effective parenting.



The Savings on Early Intervention

- The cost of supporting this one woman was approximately £165,000.
- Each Enhanced Midwife holds a caseload at anyone time of between **25 – 30**, with their annual salary being between **£34,000 - £37,000**

25 x £165,000 = Potential savings per Enhanced Midwife in the region of

£4 MILLION POUNDS!!!

Physical Disability and Pregnancy

Liverpool Women's



- Booked for maternity care and referred to a Consultant and Consultant Anaesthetist during their pregnancy to discuss plan of care, mode of delivery and preparation for c/section if **required**/chose.
- The aim of the care provided to disabled women who deliver at LWH, is to empower parents to be able to make informed choices about their care.



Baby Buddy App

- Best Beginnings Baby Buddy App is a perfect tool for all mothers including those with disabilities.
- It has information in small chunks with simple and clear language.
- It has clear videos for mums regarding breastfeeding and nappy changing.
- It has a dictionary of words for mums to look up so they are aware of the language used.
- It is accessible 24 hours a day.



Use Of Social Media

- NHS internet sites use videos to show how to bathe a baby.
- Use of the breastfeeding app to show how a baby attaches and feeds at the breast.
- Pictures are useful, with step by step instructions on tasks (feeding, laying baby down safely and bathing).
- Maternity Assist at LWH.

On-going Support

- Parents with a disability may require ongoing support therefore it is crucial following discharge from maternity services to link families to appropriate services:-
- Peer support services in the community /Homestart
- Children's Centres
- Family Support Services
- Parent Infant Mental Health Services that support the parent and child relationship.



Birth and Disability

- Positive role models should be used, organisations and women who have experienced birth with a disability. Peer support groups to discuss their experience and support
- A home birth may be more suitable for some women, it may be less threatening as many impairments do not pose and increased risk, we can still keep the woman on the normal pathway!



Birth and Disability



- Availability of partner accommodation should be made available. This is available at LWH.
- Admission the night before a planned delivery should be considered to reassure the woman, this may not be suitable for all disabled women and a individualised approach should be considered.
- Support aids should be available; back supports, height adjustable cot, etc, parents should be encouraged to bring in their own aids to support them within the hospital settings.

Midwives at LWH and Disability.

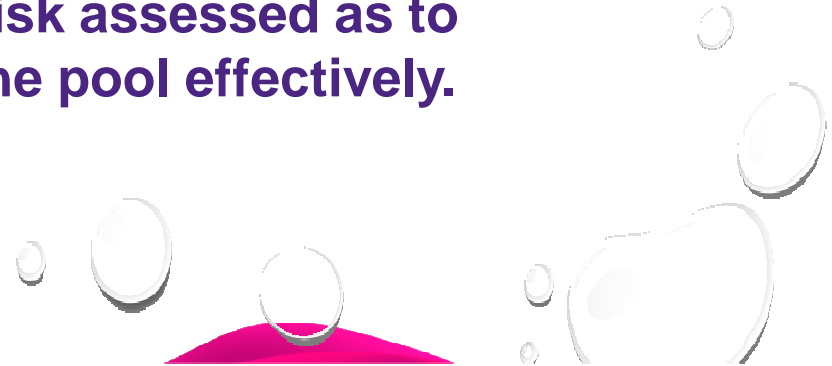


- Each woman has a named midwife who provides antenatal and postnatal care and if assessed as low risk discusses options for birth either at home or a midwifery led unit or Consultant Unit.
- Women who have delivered in our midwifery led unit report of more relaxed environment with one to one support from their midwife.



Low risk obstetrically

- LWH Midwifery Led Unit is manned 24 hours a day by midwives who are highly trained in providing midwifery care for women who are low risk.
- Midwifery Led Unit offers a home from home experience with the latest up to date birth aids to support the woman.
- Women can choose to use the pool as pain relief and give birth in the pool, a plan for their care is discussed on admission so that the woman feels comfortable.
- **E.G Women with a disability are risk assessed as to whether they can enter and exit the pool effectively.**



Birth Pool used for a home delivery.

Liverpool Women's



Liverpool Women's Hospital

Liverpool Women's



<https://vimeo.com/139683102>



Case study

Liverpool Women's



- Mum x was a mum who had the lower left leg amputated after a meningitis infection at the age of 10 years.
- She was expecting her first baby and presented at booking 12 weeks gestation.
- She became very upset at the booking visit informing staff that she was worried about coping with a baby.
- She was referred to an enhanced midwife who provided one to one midwifery care at home.
- This care was provided at a time that was suitable for her and her partner. Thus was important as she wanted her partner included in any decisions made regarding the birth.

Case study

Liverpool Women's



- She had hyperemesis and found it difficult to cope until she had her anomaly scan at 20 weeks.
- She said 'It didn't seem real' and until she seen her baby on the scan and was told everything appeared ok she could start enjoying her pregnancy.
- Enhanced midwife continued to provide antenatal care at home and obstetrically she remained low risk, she was offered a referral to our Consultant Midwife with regards to birth and what support she required with regards to support aids, use of pool, and pain relief.
- She was shown the pool availability and was asked to get into the pool to show that she was able to get in and out if required. She felt that this was a good option for pain relief.

Case Study

Liverpool Women's



- At 38+ 4 days she contacted the enhanced midwife as she thought she was in labour and her pains were becoming stronger.
- The enhanced midwife stayed to support her at home and assessed her early labour signs. She had used a 'TENS' previously for back pain and used it for the latent phase of labour.
- When she was examined at home she was 5 cm and was becoming uncomfortable with the pain . Her partner who had supported her by providing words of reassurance transferred her to the Midwifery Led Unit at LWH

Case study

Liverpool Women's



- She used the pool for pain relief and progressed through her labour using Entonox.
- She delivered a healthy son 7 hours later and got out of the pool and delivered her placenta by putting her baby to the breast. She had a 2nd degree tear which required suturing this was completed by the midwife. EBL 350ML.
- She decided to stay in hospital over night so she could be supported to breast feed her baby and her partner was offered to stay without charge.
- **ALL CARE WAS DELIVERED BY THE MIDWIFE**

HVALA

Any Questions!

Liverpool Womens Hospital

Jenny Butters Matron for Outpatient Services
Carmel Doyle Enhanced Midwife (LWH).



Liverpool Womens Hospital



- Largest free standing maternity unit in Europe.
- 2016-2017= 8450 births
- 2500 took place on the Midwifery Led Unit
- 100 home births
- Csection rate 28%
- IOL-33%



Liverpool Womens Hospital



- Employ approx 300 midwives.
- 12 obstetricians
- 1 Consultant Midwife in normality
- Infant Feeding Support Team
- Fetal Medicine Unit
- 40 maternity support workers
- Enhanced Midwifery team- look after vulnerable women.





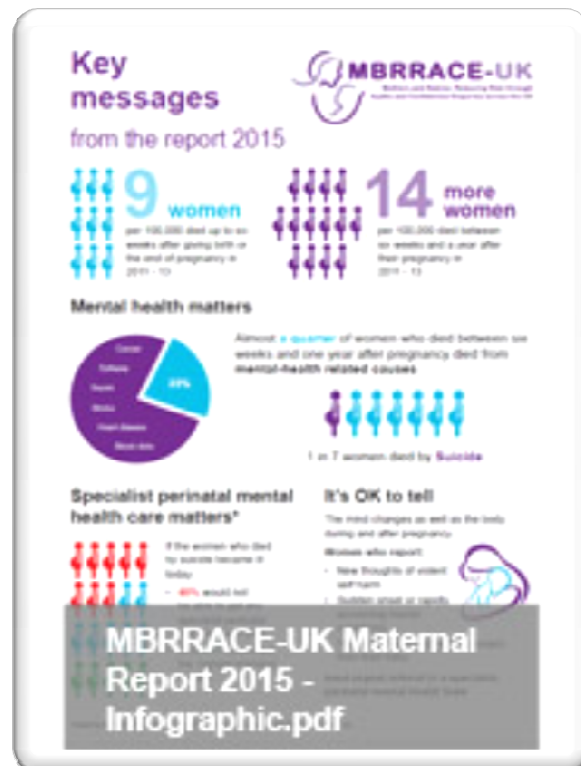
A womans Journey



- Choice- the woman books directly with LWH, and is booked in the community by her named midwife.
- Continuity of care is key to high quality safe midwifery service
- Allows time to build a trusting relationship which provides a foundation for women to become empowered to make choices regarding their care.



Drivers for Improvements in Maternity Care.



Risk Assessment




- Women are risked assessed throughout pregnancy –obstetric, medical and social factors are all considered and plan of care put in place using clinical pathways and guidelines.
- NICE Guidelines Antenatal and Postnatal Care (2014).
- Individual plan of care for women taking into account factors such as disability, mental health issues and social issues. We provide a holistic approach to person centred care.

Antenatal Screening



- Equitable offer to all women include :-
 - Screening for chromosomal abnormalities for reproductive choices.
 - Infectious disease screening : HIV, Syphilis, HepB, Ultrasound scanning for dating and screening for fetal abnormality.
 - FBC, blood group and haemoglobinopathies.

- Nutrition and diet, including vitamin D supplementation for women at risk of vitamin D deficiency, and details of the [Healthy Start programme](#)
 - Exercise, including pelvic floor exercises
 - Smoking, Drugs and Alcohol
 - Pregnancy Care Pathway
- 

Antenatal Pathway Schedule



- Primips- will receive 9 antenatal visits by named midwife and two ultrasound scans.
- Multips- will receive 7 antenatal visits and two ultrasound scans.
- Every woman is offered a 36 week visit at home to discuss pain relief, birth place, postnatal provision (safe sleeping environment for baby).
- This plan is made with a focus of the woman being the centre of care.

Tour of Our Unit.

Liverpool Women's



<https://vimeo.com/139683102>



Intrapartum

Liverpool Women's



- Midwives are the lead professionals in normal birth.
- Women are educated and advised antenatally regarding optimal positions for birth and how to recognise and cope with labour.
- Women who are assessed as low risk are encouraged to stay at home for as long as they are comfortable.
- Additionally women with more high risk pregnancy (ie- VBAC are encouraged to be mobile and consider use of pool for pain relief and birth).



HOME BIRTH



Liverpool Women's

- Birth Place 2011- for multiparous women home birth is as safe as hospital birth reducing the risk of a cascade of intervention.
- Breastfeeding within homebirths increases and bonding attachment is less medicalised.
- Women report that they feel the experience is more fulfilling and speak about having choice during their birth.
- We practice delayed cord clamping for women as up to date evidence based research shows better blood/O₂ exchange.



Perineal trauma

Liverpool Women's



- Routine episiotomy is not normal practice within our hospital.
- Midwives use evidenced based research and choice for women
- RCM recommends that there are instances when a midwife may need to perform the procedure (Royal College of Midwives, 2012).
- Fetal distress, instrumental delivery, breech of face presentation, to deal with the tissues with female genital mutilation (FGM)

- In 2015 Liverpool Womens Hospital midwives used hands on the perineum in 95% of their vaginal deliveries.
- Royal College of Midwives recognise that midwives are autonomous practitioners and that they practice with up to date evidence based research.
- Women are at the centre of their plan of care from the beginning of their journey in maternity care.





Skin to Skin



Liverpool Women's

- Regulates baby's temperature and heart rate.
- Keeps baby warm
- Stimulates breastfeeding behaviour
- Supports mother baby bonding and attachment.



Infant Feeding

Liverpool Women's Hospital have achieved UNICEF INITIATIVE NEW STANDARDS (2015).

- All midwives are trained to provide Women with education in breastfeeding.
- All Midwives are trained in supporting Mum in building a relationship with her baby in utero and following delivery.
- All Women are offered a infant feeding workshop either in a group environment, or one to one workshop.

Postnatal Care

Liverpool Women's



- Women stay in hospital for as long as necessary but with an understanding that home is the best place for mothers, babies and families.
- Enhanced pathway for csection admitted on the day of surgery and discharged home the next day. Postnatal care is then continued at home by experienced midwives.
- All women receive a package of postnatal care and then discharged to the care of the health visitor and GP.

Enhanced postnatal care for vulnerable women.

Liverpool Women's



- Vulnerable women are provided with a bespoke package of postnatal care depending on need.
- 1:4 suffer poor mental health in pregnancy therefore a majority of the vulnerable require support regarding mental health and linking into appropriate services ie:- LWH Perinatal Mental Health Team, Children Centres, Health Visitors, voluntary services.



Maintaining Safety of workforce and women.



- Audit services in order to ensure continuous improvement and effectiveness. (PDSA)
- As registered midwives we follow a code of conduct and are regulated by the Nursing and Midwifery Council.
- Follow up to date guidelines determined by evidenced based research.
- We are influenced by national drivers ie- Better Births.
- Revalidation including CPD for staff.



Service User Experience



- Feedback is received from women and families which influences service provision.
- PALS
- Complaints
- Friends and family Test
- PICKER Test- national survey
- Social Media.





END



Liverpool Women's

THANK YOU

Any Questions ???