



Paige's Story and the Maternity Passport

Shared by
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P was booked into maternity services in her third pregnancy and was noted to have two previous babies, both baby's were smaller than expected and therefore P was planned to have serial growth scans.

P's baby was noted to be smaller than expected during pregnancy but was growing along the same growth line. In May 2021 at 34 weeks and 5 days P attended her planned growth scan and again the baby was smaller than expected but remained on the same growth line, the fluid around the baby was normal however the Doppler was high (this can indicate that the placenta is no longer functioning as well)

A plan was made for a repeat scan in 2 days to check the Doppler. At each appointment P was asked if she was happy with the movements and she always nodded in agreement



P returned as planned at 35 weeks for a repeat scan and sadly the scan revealed that baby Paige had sadly died

P was admitted to the ward and had a caesarean birth which was in keeping with her wishes and baby Paige was stillborn later that day.

P was supported to spend time with baby Paige using the Cuddle Cot and helped to create ever lasting memories



Reflection



The family were initially invited to a meeting to discuss the review findings however due to a breakdown in communication the meeting did not conclude fully.

Following further investigation and over a year later the family were invited to a further meeting and a PALS advisor was present for support.

The review findings were shared and the family's questions were answered, although it was a very sad and difficult meeting for all involved it was also invaluable opportunity for learning



Reflections from the meeting

P is autistic, however this was not explored or considered during her pregnancy or following birth and there was a missed opportunity to implement adjustments to enhance her care

P recalled the question at each appointment "are you happy with the baby's movements?". P shared that due to being autistic she had not understood the nuances of the question but felt compelled to nod in agreement and would later ask her Mum what it meant. P shared that asking a direct question would have aided her understanding and supported her to feel included

The review team concluded that this would have been unlikely to alter the outcome for Paige but was a vital point for learning



All Wales Maternity Record

Cofnod Mamolaeth Cymru Gyfan

Antenatal Care / Gofal Cynenedigol

Reduced fetal movements admission
stickers attached here /
Lle i roi sticeri am leihad yn symudiadau'r ffetws



Birth is not only about making babies. It's about making mothers, strong competent healthy mothers who trust in themselves and believe in their inner strength

Mae genedigfaeth yn fwy na chreu babi. Mae'n golygu creu mamau a'r rheini'n famau medrus, cryf ac iach sy'n ymddiried ymddynt eu hunain ac sy'n credu yn eu cryfder mesonol

— Barbara Katz Rothman (author & sociologist / awdur a chymdelthasegydd)

Name / Enw:	
Likes to be called / Pronounced	
Yr enw rydw i'n ei ffafrio:	
Pronouns / Rhagenwau	
Address / Cyfeiriad:	
Postcode / Cod post:	
Date of birth / Dyddiad geni:	/ / Age / Oed:

Contact Details / Rhifau Ffôn	
Home Cartref:	
Email Ebst:	
Mobile Symudol:	
NHS No / Rhif GIG:	
Unit No. / Rhif Uned.	

Maiden name / Enw morwynol	
Previous surname / Cyfenw blaenorol	
Faith/Religion / Fydd/Crefydd	
Preferred language / Iaith ddewisol	
Country of Origin / Man geni gwreiddiol	
Interpreter required / A oes angen dehonglwr?	
Assistance needed with reading/writing required / Angen cymorth gyda darllen/ysgrifennu?	

Last menstrual period (LMP) / Dyddiad misglwyf Diwethaf	
When is my baby due / Pryd fydd fy mabi'n cael ei eni?	
Emergency Contact / Cyswllt Mewn Argyfwng (if different / os yw'n wahanol)	

Urgent contact number / Rhif cyswllt brys:	Consultant led unit / Uned dan arweiniad ymgynghorwyr:
Community midwife / Bydwraig gymunedol:	
Antenatal clinic / Clinig cyn-geni:	Midwifery led unit / Uned dan arweiniad bydwragedd:
When in labour Contact / Cysylltiad Pan yn Esgor:	
Non urgent Contact Number / Cysylltiad Di frys:	

Paige's Legacy

Following the team a small team of clinicians got together to review the All Wales Maternity Record and identified that there was no specific question in relation to a learning difficulty


HDUHB implemented an individualised sticker in each maternity handheld record to ensure that this question is asked inclusively of all women / birth person

Do you consider yourself to have any additional needs such as Autism/Dyspraxia/ Asperger's/ Dyslexia? Yes/ No
Do you need any extra support? Yes/No

**P contributed to development of the
passport at each stage in memory of
Paige**


**The Learning Disability Team were also
integral to development of the tool along
with the Maternity Experience Midwife**






Jan: Disability passport needs identified from case study - maternity experience midwife started researching similar passports in other health boards- unable to find anything specific to maternity – paediatric passport already in use in the health board, and a generic disability passport widely used in the NHS – but none specific to the needs of maternity practice.


Mat exp started to design a passport with an amalgamation of the different passports available, but conscious it needed to only be one A4 page long so it was easy to read, and would be read by health practitioners. Maternity passport was designed. However, mat exp mw realised needed more input to ensure the language was correct.




Jan: Maternity Experience Midwife contacted Learning and Disability Department for assistance in having the passport peer reviewed, and to also ensure the language within the passport was easy to read, the layout and design would be easy to review, and to see if they had any groups that could review the document before it was made public. Acknowledging outside the sphere of a midwife, therefore collaborated with speciality services



Feb: Learning and Disability department: the interim Head of Adult and Inpatient Learning Disabilities, and the Professional Lead of LD nursing assisted in adjusting the questions to be used to identify those with learning needs, and took it to the service user led easy read group for comment.



HB wide learning commenced to get the passport out into the public domain, once approved by guidelines meeting and patient experience team for Hywel dda. Translated into Welsh, and a sticker was designed to add to the front of the maternity notes to identify those who had a maternity passport. The questions to identify those who needed to be filling in the passport were added to Page 1 of the all wales maternity record so the questions could be asked at the start of the appointment.



May: Mat passport being used publicly.

Maternity Passport



Maternity Passport



I like to be known as:



My preferred language is:



How to communicate with me:



Person with me:

Person who needs to be with me for appointments:



My Health needs:

Medications I take:



How I show if I am in pain or unwell:



What to do if I'm anxious:

Reasonable adjustments (Please circle the adjustments you would like)

Longer appointment slots



Partner to stay with me at all times



No medical words



Videos or easy to read leaflets



Write all information down in an easy read format



Check that I have understood



Talk slowly



Low lighting in appointments



Please find a quiet place to talk



Other reasonable adjustments

Midwife to sign and date:





Pasbort Mamolaeth



Bwrdd Iechyd Prifysgol
Hywel Dda
University Health Board



Hoffwn i chi fy ngalw yn:



Fy newis iaith yw:



Sut i gyfathrebu â fi:



Pwy sydd gyda fi:

Y person sydd angen bod gyda
fi mewn apwyntiadau:



Fy anghenion iechyd:

Fy meddyginiaethau:



Sut rwy'n dangos os ydw i mewn poen neu'n sâl:

Beth i'w wneud os ydw i'n bryderus:

Newidiadau rhesymol (rhewch gylch am y newidiadau y byddech yn hoffi)

Slotiau apwyntiad hirach



Fideos neu dafienni
hawdd eu deall



Siarad yn arafach



Partner i aros gyda
mi bob amser



Ysgrifennu'r holl wybodaeth
mewn ffordd hawdd ei ddeall



Golau isel mewn apwyntiadau



Dim geiriau meddygol



Gwneud yn siŵr fy
mod wedi deall



Mynd i le tawel i
siarad



Newidiadau rhesymol arall

Bydwraig i lofnodi a rhoi'r dyddiad:







About Me / Amdanaf i

This sheet is a summary of the things that are materially important to me that I wish to share with healthcare providers involved in the care of my pregnancy. It is not part of the medical records which should still be reviewed in full. / Mae'r daflen hon yn grynodeb o'r pethau sydd o bwys sylweddol i mi yn hofhyn eu rhanu â darparwyd gofal iechyd sy'n ymwneud â gofalu am fy meichlogrwydd. Nid yw'n rhan o'r cotnodion meddygol y dylid eu hadolygu'n llawn o hyd.

Please read the following before any consultations /

Darllenwch y canlynol cyn unrhyw ymgynghoriadau.

Name / Enw:

Address /

Cyfeiriad:

My home and family life / Fy mywyd cartref a theulu



My past pregnancies / Fy meichlogrwydd yn y gorffennol



My current pregnancy / Fy meichlogrwydd presennol



How to communicate with me / Sut i gyfathrebu â fi



Do you have any additional needs? / Pwy sydd gyda fi



My health needs / Fy meddyginiaethau



Person who needs to be with me at appointments? / Y person sydd angen bod gyda fi mewn apwyntiadau

How I show if I am in pain or unwell /

Sut rwy'n dangos os ydw i mewn poen neu'n sâl



What to do if I'm anxious /

Beth i'w wneud os ydw i'n bryderus



Reasonable adjustments (Please circle the adjustments you would like) / Newidadau rhesymol (browch gyfrif am y newidadau y bydddech yn hoffi)

	Individual appointment planning / Sioeiau apwyntiad heoch		Partner/partner advocate to accompany me to help me understand what is happening / Partner/partner gartrefndwr i fynd gyda mi i'm helpu i ddeall beth sy'n digwydd		Check that I have understood / Gwneud yn siŵr fy mod deall deall
	Media resources or easy read leaflets / Ffôn neu dafenni hantol eu deall		Write all information down in an easy to read format / Ffôn neu dafenni hantol eu deall		Please find a quiet place to talk / Myned i le tawel i siarad
	Talk slowly / Siarad yn arafach		Low lighting in appointments / Gofal i'w mewn apwyntiadau		Information to be provided in my own language / Gwybodaeth i'w darparu yn fy iaith fy hun

Other reasonable adjustments / Newidadau rhesymol arall

What else is important to me / Beth arall sy'n bwysig i mi



Love Alba

Midwife to sign and date /
Bydwraig i llofnod a thar'i dyddiad

Sign / Llofnod

Date / Dyddiad