

Shared by Cerian Llewelyn 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





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

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



**Antenatal Care / Gofal Cynenedigol** 



🏅 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 aenediaaeth yn fuy na chreu babis Mae'n aduau creu mamau a'r rheini'n

	f ac iach sy'n ymuldiried ynddyne eu hunain ac sy'n credu yn - Barbara Katz Rothman (author â sociologist / awdur a chymdeithasegydd)
Name / Enw:	Contact Details / Rhifau Ffôn
Likes to be called / Pronounced Yr enw rydw i'n ei ffafrio: Pronouns /	Home Cartref: Email Ebost:
Rhagenwau  Address / Cyfeiriad:	Mobile Symudol:
	NHS No / Rhif GIG:
Postcode / Cod post:  Date of birth /	Unit No. / Rhif Uned.
Maiden name / Enw morwynol	
Previous surname / Cyfenw blaenorol	
Faith/Religion / Ffydd/Crefydd	
Preferred language / laith ddewisol	
Country of Origin / Man geni gwreiddiol	
Interpreter required / A oes angen dehonglwr?	
Assistance needed with reading/writing required / Angen cymorth gyda darrlen/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:	

AWMR 08/23 V2

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**





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



Videos or easy to read leaflets



Talk slowly



Partner to stay with me at all times



Write all information down in an easy read format



Low lighting in appointments



Check that I have understood

No medical words



Please find a quiet place to talk



Other reasonable adjustments

Midwife to sign and date:







### **Pasbort Mamolaeth**





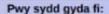
Hoffwn i chi fy ngalw yn:



Fy newis iaith yw:



Sut i gyfathrebu å 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 (rhowch 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



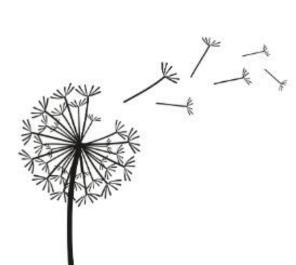
Mynd i le tawel i siarad



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 programcy, it is not part of the medical records which should still be reviewed in full. I Macri duffer hon yo grynodeb o'r pethau sydd o buyrs sylvendoloi I mil y hithan eu rhannu. 3 drapamary godal lectryd y'n promised 3 grafalu am fly meichiograydd. Nid yw'n rhan o'r cothodion meddygol y dylid eu haddiggu'n llawn o hyd.

### Please

Name / Envi:	
Address /	

records which should still be reviewed in full. I Macin still to buye sylwedial I mill yn hathwr eu rhannu â dirparniyr gofi ly meichiognwydd. Nid yw'n rhan o'r cothodion meddygol Please read the following before any comultation Darllemeth y canlynol cyn unrhyw ymgynghoriadau.	al lechyd sy'n ymwneud â gofalu am y dylid eu hadolygu'n llawn o hyd.	Cyleiriad:			
My home and family life / Fy mywyd cartref a theuluol	My past pregn	My past pregnancies J Fy meichiograydd yn y gorffennol			
1	3				
My current programcy / Fy meichingrwydd presennol	How to comm	unicate with me / Sut I gyfarfireba & II			
9					
Do you have any additional needs? / Pwy sydd gyda fi	My health nee	ds / Fy meddygiriaethau			
<b>①</b>	4				
Person who needs to be with me at appointments? J Y person sydd argen bod gyda 'il mewn apwyrdadau					
How I show if I am in pain or unwell / Sut rey'n danges os yow i mewn poen neu'n sië		What to do if I'm analous / Seth I'w wnexd on you i'n brydenus			
<b>1</b>	•				
Reasonable adjustments (Please circle the adjustments	s you would like) I Newschadau rhesys	ool (howch gyldr am y newiskadau y byddech yn hoff))			
Incluidual appointment planning / Similar appointment planning /	Pertnerforth partnerfadvocate to according to help me understand what is hard Partner/partner gentlerforer if you got help u i docat help oy'n digwydd.	opposing Check that I have understood /			
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	Individual appointment planning / Sisting appoint at brack	9	Pertnerforth partnerfadvocate to accompany me to help me undertotaed what is happening ? Rantempartner geniterfore i frod gyda mi fin help u i date all bertr sy'n digwydd.	0	Check that I have understood / Gwnesd proswer ly road used deal
	Media resources or easy read leaflets Fideco nea deflects haveld so seal		Write all information down in an easy to read format / Yugiflemo's holl wybodaeth meen flord hawdd ei ddeall	-	Please find a quiet place to talk. Myrefi le towel i siacad
B	Talk slowly / Slared yn arafach	•	Low lighting in appointments./ Golacisel newn apsymtatas	0	Information to be provided in my own language / Gwybosbieth i'm darpan; yo ly with ly hun

Other reasonable adjustments / Newidiadau rhesprodiarall	What else is important to me / Beth anali sy'n twysig i mi			
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A. Midwife to sign and date	y Sign I knopt I	Data / Dycocali	<del>- \                                   </del>	

