PARENT-CENTRED GUIDELINES FOR CARE AFTER DIAGNOSIS OF AN NHS FASP CONDITION

Antenatal Results & Choices

These guidelines are not designed to provide detailed instruction for clinical management after diagnosis, or to be entirely prescriptive. The aim is to describe the general principles all parents should expect as standard care.

The target readership is any healthcare professional involved in the care of parents through antenatal diagnosis and its consequences. Expectant parents facing diagnosis may also find it helpful to read certain sections so they have an idea of what to expect from their healthcare team.

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1. Introduction

Background

For well over a decade the NHS Fetal Anomaly Screening Programme (NHS FASP) and the Screening Quality Assurance Service (SQAS) have helped to establish and maintain a high-quality antenatal screening service across England. Standardisation and quality assurance processes mean that parents in all regions of the country can expect a similar level of care through antenatal screening. This national consistency does not extend beyond the screening pathway when a diagnosis is made, as instruction is given to follow local protocols. Many units provide excellent, well-coordinated care to parents when their baby has a suspected or confirmed genetic and/or structural condition, but this is locally, rather than nationally driven.

The UK-wide charity Antenatal Results and Choices (ARC) noted inconsistencies in care through feedback from parents on its national helpline and from contact with healthcare professionals through its professional training programme. ARC decided to form an expert working group to collaborate on a set of practical guidelines that could be applied in all NHS settings where antenatal diagnosis might occur. Membership of the group can be found in the appendices.

We recognise that these guidelines relate to an English context, but we hope what follows will be helpful and often applicable in the devolved nations.

These guidelines focus on the NHS FASP screened for conditions: Down's syndrome, Edwards' syndrome, Patau's syndrome, anencephaly, spina bifida, major cardiac conditions, congenital diaphragmatic hernia, severe skeletal dysplasia, bilateral renal agenesis, cleft lip, exomphalos and gastroschisis, as well as the relatively commonly detected findings of increased nuchal fold, ventriculomegaly, renal pelvis dilatation (RPD) and echogenic bowel.

A note on language

We have chosen to use the terms 'parents' and 'baby' because these are the terms used by most people facing a prenatal diagnosis. We acknowledge that this terminology will not feel right for everybody. It is important that professionals take the lead from the people they are caring for regarding their language preferences and how they wish to identify themselves.

Key components of high-quality care

Evidence-based individualised clinical care should be provided to parents after an antenatal diagnosis. However, particularly given that expectant parents given a diagnosis are likely to be distressed, effective communication is as important as the technical and practical elements of the care pathway. This includes communication with parents and between healthcare professionals.

Communication with parents

Sensitive individualised communication with parents is essential. A positive screening result or suspected finding is likely to have significant psychological impact on parents. This means that their ability to take in information may be impaired.

Communication between healthcare professionals - multidisciplinary team working

There will often be a range of healthcare professionals involved in antenatal diagnosis and ongoing care. This may include administrative staff, clinical geneticists, fetal cardiologists, fetal medicine specialists, genetic counsellors, healthcare assistants, midwives, neonatologists, paediatricians and paediatric surgeons, sonographers and obstetricians. It is important that all professionals who see parents introduce themselves and explain their role clearly. Parents may be seen both at their local hospital and a referral fetal medicine specialist unit or tertiary centre. This will require successful multi-disciplinary team working.

It can be helpful for staff from local referring units to visit specialist fetal medicine centres to meet teams and be able to prepare parents for what to expect from appointments. It is also important that referral units provide regular and timely feedback to local hospitals to update them on individual care plans. Good working relationships and open communication between sites will benefit parent care. It will be beneficial if a senior clinician identifies themselves as taking 'ownership' of the case to aid continuity.

NHS England is in the process of completing a service specification for fetal medicine services, which will be helpful in defining levels of service provision and how this relates to prenatal diagnosis.

When there is multidisciplinary team involvement, members of the team should be known to each other to foster an effective working relationship. While there may be differing professional opinions on individual care, every effort should be made to provide parents with consistent information and to explain why differences of interpretation might have occurred.

Whatever the diagnosis, specialist midwives, usually screening or fetal medicine midwives have a crucial role in ensuring parents experience continuity of care, have individualised support and a point of contact between appointments.

Equity of care

These guidelines are based on the principle of high-quality individualised care for all parents facing an antenatal diagnosis. As outlined above, attention should be paid to effective and empathetic communication as many parents will be anxious and distressed. There are likely to be extra challenges for those for whom English is not their first language and any interpreting needs should be met. It is important to be culturally sensitive to parents from diverse ethnic and religious backgrounds but not to make assumptions about their management preferences.

Some parents may have extra needs, perhaps because of learning difficulty, mental health issues or sensory impairments. Appropriate help should be engaged, e.g. advocacy services, when necessary to ensure optimal care.

Supporting personal informed choice

The principle of personal informed choice underpins the NHS Fetal Anomaly Screening Programme and must extend through antenatal diagnosis. Parents must have access to NHS approved pre-test information and the opportunity to discuss their antenatal screening options before having any tests. Protocols should be in place to ensure that all staff involved in antenatal care, doctors, midwives and sonographers know their part in the process of facilitating personal informed choice. However, there is no evidence to suggest that good pre-test knowledge will mitigate against the psychological impact of a diagnosis.

There will also be parents who decline screening for Down's syndrome, Edwards' syndrome and Patau's syndrome but end up with a diagnosis because of an unexpected scan finding. No assumptions based on their screening choices should be made about how parents may react or choose to proceed when a diagnosis is made.

2. Making the diagnosis

i. Diagnosis of T21/T18/T13

In England all women are offered screening for Down's syndrome (T21), Edwards' syndrome (T18) and Patau's syndrome (T13). The recommended test for those who want screening is the combined screening test performed between 11^{+2} and 14^{+1} weeks of pregnancy, with the quadruple blood test available from 14^{+2} – 20^{+0} weeks for those who do not make the window for the combined test or who are unable to complete it.

Parents with a chance result from screening of between 1 in 2 to 1 in 150 at term are offered three options. They can have non-invasive prenatal testing (NIPT) to give a more accurate assessment of the chance of having one of the trisomies, invasive prenatal diagnosis through CVS or amniocentesis, or the option of no further testing.

***Key point:** Parents must be aware that even if they decline screening for any of the trisomies, unexpected findings (including a raised nuchal translucency of 3.5mm or more) may still be detected at the first trimester dating scan and will be reported.*

Increased nuchal translucency (NT) measurement

According to NHS FASP guidance*, if during the 11^{+0} – 14^{+0} week scan the NT measures 3.5mm or more, parents must be informed of the measurement, even if they had declined combined screening (they may wish to revisit this decision in the light of the raised NT). This is because the excess fluid could indicate a condition that is genetic or structural, and not restricted to the common trisomies.

A raised NT is likely to be difficult news for expectant parents as the finding could point to a number of possible outcomes. **They will need careful counselling that acknowledges the uncertainties ahead.** The option of an initial discussion about the finding or signposting to support should be given before parents leave the hospital.

*https://www.gov.uk/government/publications/fetal-anomaly-screening-programme-handbook

It can be helpful for parents to be given written information about raised NT to read in their own time. An example is here: https://www.wsh.nhs.uk/CMS-Documents/Patient-leaflets/Maternity/6869-Raised-nuchal-translucency-NT-identified-at-dating-scan.pdf. Published statistics (which are now dated) related to the outcomes of pregnancies with high NT measurements may provoke significant anxiety. Some parents may decide they cannot tolerate the uncertainties ahead and opt to terminate the pregnancy without waiting for further testing.

News of the increased NT means that some parents, who initially declined screening for the three main trisomies, may wish to revisit their decision and undergo this screening. The chance of a condition being found in a baby is related to the size of the NT.

***Key point:** All parents with a raised NT must be offered a fetal medicine appointment to discuss possible outcomes, assess early fetal anatomy and to discuss genetic testing and a fetal echocardiogram.*

The place of NIPT in the diagnostic pathway

NIPT has been available in the private sector in England since 2012. It is now offered as a contingent test within NHS screening for T21, T18 and T13, but it remains heavily marketed in the private sector. Counselling about the testing and information provided by private providers can be variable. This may lead to some parents mistakenly believing that NIPT is diagnostic.

If NIPT predicts T21, those who know they would wish to continue the pregnancy if their baby had T21 may decide to assume their baby has the condition without gaining confirmation. However, parents who plan to end a pregnancy on the basis of an NIPT result need careful counselling about only invasive testing being conclusive, so they understand that they are making the decision based on a screening result, rather than a definitive diagnosis. This means they need to know that there is a chance they could terminate a pregnancy where the baby does not have the condition.

The way NIPT is discussed and offered as a contingent screen within the NHS should mean that parents have a more realistic understanding of its limitations. This is particularly important in relation to T18/T13 in the absence of ultrasound-detected findings.

False positive NIPT results may arise as a result of confined placental mosaicism. Parents also need to know that if their combined test result is 1 in 10 or higher, the false negative rate for NIPT increases.

After counselling about the limitations of NIPT, some parents who would not consider termination may decide to avoid invasive testing and use a higher chance NIPT to prepare themselves for having a baby with a trisomy.

***Key point:** Comprehensive pre- and post-test counselling is vital to ensure parents understand what their NIPT result means.*

Useful guidance: https://www.rcog.org.uk/guidance/browse-all-guidance/other-guidelines-and-reports/supporting-women-and-their-partners-through-prenatal-screening-for-downs-syndrome-edwards-syndrome-and-pataus-syndrome/

Invasive diagnostic testing for T21/18/13

Information on the technical aspects of chorionic villus sampling (CVS) and amniocentesis can be found here: https://www.rcog.org.uk/guidance/browse-all-guidance/green-top-guidelines/amniocentesis-and-chorionic-villus-sampling-green-top-guideline-no-8/

When possible, women should be given a choice of procedure, with clear explanation as to when waiting for amniocentesis may be recommended. They need to know what each procedure involves and where it will take place.

***Key point:** When considering CVS, if there are no visible scan findings in the baby, parents must be alerted to the small possibility of a positive result being due to confined placental mosaicism (CPM) and advised that waiting for amniocentesis would avoid this.*

Some parents may find it too difficult to wait weeks for an amniocentesis. If they do opt for CVS, they should be counselled to wait for full analysis of the CVS sample (karyotype or microarray) if they intend to have a termination of pregnancy because of the possibility of a false positive and thus terminating a baby who does not have the condition (particularly in the absence of scan findings).

Parents should be made aware of exactly what tests will be carried out on the sample and what they are testing for, the turnaround time for getting the results, and that occasionally there may be delays in getting the "second result" (usually microarray).

If parents opt for diagnostic testing in a multiple pregnancy, pre-test counselling by a fetal medicine clinician experienced in invasive testing for multiple pregnancy should include testing one vs. both babies and the risks of miscarriage with either approach. There will also need to be detailed mapping of the babies before invasive testing.

***Key point:** In the case of multiple pregnancy, CVS or amniocentesis should be carried out at a tertiary fetal medicine unit.*

Reporting diagnostic results to parents

Before a diagnostic procedure takes place, parents should be made aware of when and how the results will be communicated to them (most often results will be given over the phone).

***Key point:** Diagnostic results are best given by someone who knows the parents and is confident and competent in sensitively disclosing what could be difficult news or complex information. A face-to-face appointment to discuss ongoing care should be offered as soon as practically possible.*

While many parents will feel relief when a CVS or amniocentesis result comes back saying the baby does not have the suspected condition, others will struggle with residual anxiety, especially if there were unexpected scan findings. This should be acknowledged, and support offered when necessary. Occasionally, there may be a need to discuss the value of additional genetic tests, which will require a review with the clinical genetics team.

When T21 is diagnosed

A result showing the baby has T21 should be clearly and sensitively conveyed, for example:

'The CVS result has confirmed that your baby definitely has Down's syndrome.'

'Your amniocentesis result shows for certain that your baby has Down's syndrome.'

'You may need time to take in this information, please feel able to call back later and we can set up an appointment as soon as you want to give you the chance to ask questions and discuss your next steps.'

No assumptions should be made about how parents might react to the news, but they will appreciate an empathetic response if they are distressed.

Professionals should make sure parents are aware of all their options and take the lead from them regarding the next steps. No assumptions should be made about how they might wish to proceed as parents may change their decision-making when a diagnosis in their baby is a reality.

Parents need access to information on what the diagnosis of Down's syndrome might mean for their child and family. This includes the range of possible outcomes for children and adults with the condition. They may want to speak to a neonatologist / paediatrician or learning disability nurse to find out more about their child's potential needs. The Down's Syndrome Association can provide up to date information and may be able to put expectant parents in touch with support groups in their local area.

Parents need to know that they have the option to end the pregnancy (without it being presented as the preferred option) and, if appropriate, provided with clear information on what this might involve. (see section 5 below).

***Key point:** After a diagnosis of Down's syndrome, parents must be assured that there is not a preferred decision and that they have the time they need to decide how to proceed.*

When T18 or T13 is diagnosed

The implications of T18 and T13 are very serious and parents need to know their baby is likely to die during the pregnancy or soon after birth. However, some babies do survive longer and they should be told this is a possibility.

Even if screening results have suggested one of the two conditions, having a confirmed diagnosis is likely to be distressing for parents. Termination of pregnancy should be discussed in a non-directive way. For parents who are continuing the pregnancy, the care plan should include access to specialised midwives with possible involvement of paediatric services, palliative care teams and local hospices. They may also benefit from signposting to SOFT UK, the UK charity supporting around T13 and T18.

***Key point:** After the diagnosis of any of the trisomies, parents must be reassured that whatever their decision about the future of the pregnancy, this will be fully supported by their healthcare team and a co-ordinated care plan will be agreed with them and put in place.*

ii. Diagnosis made by ultrasound

In general, ultrasound scans in pregnancy are viewed more favourably than other medical examinations. Very few parents decline the opportunity for a scan as they are keen to 'see their baby' and hope to be reassured that all is well. This can intensify the psychological impact when a scan brings unexpected news about their baby.

When unexpected news has to be given, sensitive, clear and concise explanation will be essential, along with due regard to the capacity of the parents to take in what they need to know at a time of intense shock.

Sonographers will often be the first to disclose to expectant parents that their baby or babies may not be developing as expected. They should be aware of the consensus guidelines on communicating news to parents from a scan: (INDIRA). https://eprints.whiterose.ac.uk/162880/14/ASCKS%20Framework%20guidelines.pdf

Communicating unexpected or difficult news is challenging and all sonographers should have appropriate training to help equip them with the necessary skills.

Where fetal medicine services are co-located and parents can be offered a consultation on the same day, staff should recognise that parents' ability to take in information could be impaired when they are in shock from the initial news.

***Key point:** All sonographers need training and support around communicating unexpected/difficult news*

***Key point:** Because of the psychological impact on parents of unexpected news, the sonographer should be able to call on a colleague (often a screening or fetal medicine midwife) to provide support to parents as soon as possible after the scan. For external support, parents can be signposted to ARC.*

Diagnosis following first trimester scan (dating/NT scan)

The main purpose of the first trimester scan is to date the pregnancy and, if screening is accepted, measure the nuchal translucency. However, parents need to be aware of the possibility that physical conditions may sometimes be seen at this stage and will be reported to them.

Swift referral for expert clinical opinion must be made, meeting NHS FASP standards. This will enable parents to access earlier diagnostic testing if this is appropriate and desired.

While it will most often be necessary to refer parents on to clinicians for more information, there are some conditions that will be clear to the sonographer on scan, e.g. anencephaly. It is important in these cases that, if necessary, a second confirmatory opinion is obtained as soon as possible so that there are no unnecessary delays (which are likely to add distress for parents).

Diagnosis following the 20-week screening scan

Parents must have information about the purpose of the scan before attending and choosing to proceed. They need to be aware that the sonographer will be taking measurements and checking for signs of the physical conditions screened for as part of the NHS FASP base menu.

Before commencing the scan, the sonographer should introduce themselves, explain their role and the limitations of ultrasound, so parents know that if something is detected, follow up appointments will be arranged to provide them with as much information as possible about the implications of any findings.

However good their pre-scan counselling, this will rarely mitigate against the shock of being given difficult news. If all has gone smoothly so far, it may be hard for them to accept this new reality and there can be a range of reactions. This can be challenging to deal with for sonographers. Again, regular training and support is essential.

It will be helpful for the expectant parents to have a midwife to speak to and gain support from immediately after the scan. This will be more difficult to achieve if the ultrasound department is not co-located with antenatal services. This will be essential if the sonographer has been able to make a diagnosis, in the case of anencephaly for example.

***Key points:** Sonographers should be open and honest with parents about any concerns, even if they are uncertain. Anything that goes into the notes should be explained in a clear way to the parents, with any medical terms explained sensitively.*

Diagnosis following third trimester scans

Third trimester scans are not routine for all pregnant women, but many take place to monitor the pregnancy and fetal growth, check placental position or as part of a research protocol. This means it is possible an unexpected finding could be detected that may only have become apparent at this stage of pregnancy.

Third trimester diagnosis requires sensitive and carefully coordinated management. Tertiary level fetal medicine input is likely to be needed and should be offered and arranged as quickly as possible. Parents should be offered neonatal counselling and other specialist neonatal/paediatric input, dependent on the findings.

If the findings fit the criteria of Ground E of the Abortion Act, parents have the option of a later medical termination of pregnancy, which is likely to be a distressing prospect.

***Key point:** A third trimester diagnosis can be particularly traumatic for expectant parents, access to emotional support should be provided.*

iii. Genetic/genomic testing

There will be situations when scan findings or diagnosis of an NHS FASP physical condition will prompt the offer of genetic testing. Parents need to be informed that scans alone are not able to diagnose chromosome/genetic conditions and offered invasive testing when appropriate. Some parents may wish to have a third trimester amniocentesis and there is also the option of postnatal genetic testing.

The laboratory tests carried out following CVS or amnio will depend on the indication. Testing will usually include rapid QF-PCR for trisomy 21, 18 and 13. QF-PCR can include the sex chromosomes where there is a suspicion of a sex chromosome condition such as Turner Syndrome (monosomy X). When there are unexpected scan findings, a microarray is also carried out to look for rarer chromosome conditions.

In cases where there is an increased chance of a genetic condition and where the situation fulfils eligibility criteria for genomic sequencing (R21), urgent referral to clinical genetics is required.

***Key point:** Genomic testing requires very detailed phenotyping by ultrasound scan and referral to an experienced fetal medicine unit is strongly recommended.*

The discussion around genomic sequencing is complex as parents need to be made aware of the potential benefits and limitations of genomic testing at what is often a highly anxious time.

A helpful animated video explaining R21 for parents can be found here: https://vimeo.com/862026376

Discussions about sequencing need to be sensitively handled by knowledgeable staff and ongoing support should be offered. For some indications, non-invasive prenatal diagnosis (NIPD) may be appropriate and can be offered instead of invasive testing.

Eligibility criteria for any genomic testing can be checked in the National Genomic Test Directory: https://www.england.nhs.uk/publication/national-genomic-test-directories/ . All staff involved in the pathway need to be familiar with the directory and how the referral process works to enable equitable access to testing.

***Key point:** Parents need to understand that even if a result shows no relevant finding, prenatal genetic/genomic testing cannot rule out an underlying genetic condition.*

All discussions about testing need to include the expected turn-around time for results.

Some parents may decide that they feel emotionally unable to wait for results and decide to end the pregnancy based on the scan findings where this is legally possible. In such circumstances, prior to termination of pregnancy postnatal testing should be discussed. This can also be discussed prior to birth if the parents continue the pregnancy and a palliative pathway is in place.

In order for postnatal sequencing to take place, consent should be gained from the parents to take tissue from the baby (most likely cord blood) and for blood samples to be taken from each parent. This will allow DNA, forming a 'trio' from baby, mother and father to be taken and banked. Then either exome or whole genome sequencing can be performed with clinical genetic liaison, consent from the parents and with an urgency dependent upon the clinical circumstances.

***Key point:** Parents should be informed that laboratory turn-around times for non-urgent tests are generally considerably longer than for prenatal testing.*

iv. Magnetic resonance imaging (MRI)

In certain situations where ultrasound scan has detected, for example, brain conditions, lung lesions, spina bifida or kidney conditions it may be helpful to use MRI to give a more detailed diagnosis or prognosis.

Timing of MRI scans will depend on the findings being investigated and sometimes more than one MRI may be necessary. For this reason, fetal medicine specialists are best placed to make the referral. A good source of parent friendly information is provided by the Sheffield fetal MRI service: https://www.fetalmri.co.uk/

***Key point:** Parents may have to travel some distance to access fetal MRI and should be prepared for what they might expect from the appointment and be aware that results will not be available immediately.*

3. Information about the diagnosed condition

Most parents will want as much information as possible about the condition diagnosed in their baby and particularly about what it might mean for their baby's health. Depending on the condition, it may be necessary to call on a range of clinicians to provide parents with as much detail as possible about prognosis and so will involve a multi-disciplinary team.

To complement consultations with their healthcare team, parents should be signposted to information they can access in their own time, such as the NHS information on NHS FASP conditions:
https://www.gov.uk/government/collections/fetal-anomalies-screening-conditions-diagnosis-treatment

Parents may also find it helpful to be signposted to condition specific organisations (listed in the appendices). This can give them the opportunity to learn more about the range of lived experience of children and adults with the diagnosed condition and their families.

Inevitably, many parents will use the Internet as a source of information and may need to be reminded that online sources vary in quality and medical accuracy.

When prognosis is uncertain

Aside from the NHS FASP conditions which mean the baby will not survive after birth, such as anencephaly, bilateral renal agenesis and severe skeletal dysplasia, parents will be faced with a range of potential outcomes for their baby. Clinical teams should strive to use available current evidence, their professional experience and clinical networks to help parents understand the likelihood of different outcomes in their particular case.

For parents continuing a pregnancy with an uncertain outcome, MDT involvement will often be needed with documented discussions that plan for the best-case scenario and also prepare for the worst. Care plans must take account of and properly value parents' wishes regarding the birth.

***Key point:** Gaps in evidence and uncertainties ahead are likely to be distressing for parents and this should be acknowledged.*

4. Offering care options after diagnosis

Communication and counselling

The NHS FASP is predicated on providing information to parents that enables them to make choices about their ongoing care. Antenatal diagnosis gives parents continuing the pregnancy the knowledge that the baby has a physical or genetic condition. They can then prepare themselves and their families for what might be ahead and discuss ongoing care for them and their baby with their healthcare team.

How to raise the option of termination with parents can be challenging. It is important parents know that it is simply an option and is neither expected nor favoured. One approach might be to say, *'I know this may be difficult to hear but due to this diagnosis/these findings, you have the option to end your pregnancy. It is entirely your decision, and we will fully support you if you continue or end your pregnancy'*. Non-direct language may help, such as *"Some parents decide to end the pregnancy in similar situations"* rather than talking about the option of termination which can sound insensitive to some parents.

Parents will vary in the amount of time they will need to make a decision. They should be reassured that there is no pressure, unless they are approaching 24 weeks' gestation, and the diagnosed condition does not meet the criteria for Ground E of the Abortion Act (see next section).

***Key point:** If there is time pressure, parents may need extra support as it can make what is already a distressing situation feel overwhelming.*

Legal aspects regarding termination of pregnancy

The Abortion Act (1967, as amended in 1990) covers England, Scotland and Wales. Northern Ireland has a separate law.

Terminations for fetal anomaly are legally sanctioned (with no time limit) in England, Scotland and Wales through Section 1 (1) (d) of the Abortion Act of 1967 (as amended in 1990). This is commonly referred to as 'Ground E'. The criteria are:

*'two registered medical practitioners are of the opinion, formed in good faith— (d) there is a **substantial risk** that if the child were born it would suffer from such physical or mental abnormalities as to be **seriously handicapped**;'*

Depending on the condition diagnosed, some doctors prefer to use Section 1(1)(a) (commonly known as Ground C) which allows termination if:

the pregnancy has not exceeded its 24th week and the continuance of the pregnancy would involve risk, greater than if the pregnancy were terminated, of injury to the physical or mental health of the pregnant woman.

***Key point:** Whether Ground C or E is chosen to sign off the pregnancy, this must not affect the care parents receive.*

Section 4 of the Abortion Act is a conscientious objection clause which permits doctors to refuse to participate in terminations, but which obliges them to provide treatment necessary to save the life or to prevent grave permanent injury to a pregnant woman.

The legal right to conscientious objection only covers participation in the termination procedure and this was upheld in the Supreme Court Decision in the 2014 case: *Doogan and Wood v Greater Glasgow & Clyde Health Board*. Given this, it will not be helpful for parents who wish to discuss termination to have to do so with someone who has a moral objection and may struggle with such conversations. This will need careful management by the staff team.

***Key point:** Despite a health professional's right to conscientiously object to providing abortion care, patients are entitled to receive objective and non-judgmental medical advice and treatment.*

Multiple Pregnancy

Options available to parents, will depend on the type of multiple pregnancy. If they are considering selective termination, parents will need to be counselled around risks to the surviving twin and optimal timing.

***Key point:** Discussions regarding selective termination of pregnancy must take place in a tertiary fetal medicine centre with suitably qualified and experienced clinicians.*

5. Continuing the pregnancy

Parents will vary in their reasons for continuing a pregnancy. For some it will be a difficult decision; others will trust that treatment or interventions will be successful and there will be those who would not consider termination in any circumstances. Whatever the situation, the decision to continue must be respected, known to all involved in the parents' care and recorded in their notes. An individualised care pathway should be discussed, agreed and documented.

Plans for care through pregnancy and birth need to accommodate both the best-case scenarios and make provision for the baby's condition deteriorating. Uncertainties around the outlook are likely to cause parents extra difficulties, which should be acknowledged.

While there may be changes as the pregnancy progresses, which may lead to some parents wanting to revisit their decision, this will need a sensitive approach. Some parents have described feeling judged or unsupported if asked too often about their decision to continue. It can be helpful to explain that a renewed discussion about the option of termination is based on new findings.

In some cases, invasive diagnostic procedures may be discussed to determine whether there is a genetic cause for the physical condition. Some parents wish to avoid invasive testing unless establishing a genetic/chromosomal condition will affect management of birth and immediate ongoing care.

What follows are brief guidance points concerning care that are relevant to those continuing after diagnosis of conditions on the NHS FASP menu. It should be noted that some of the conditions outlined below will form part of a multi-system condition which will affect management.

i. Conditions where the baby will not survive birth or for long after birth

E.g. anencephaly, bilateral renal agenesis, severe skeletal dysplasia. Parents who are continuing in the knowledge their baby will not survive should be offered emotional support and continuity of care by experienced trained staff. It should be noted that some parents may find it difficult to be introduced to someone named as a 'bereavement' midwife before their baby has actually died.

Discussions with a palliative care team should be offered so that parents are informed about how care might be managed and their options within the process. Every effort should be made to enable the parents to decide how they would like labour and birth to be managed and a birth plan documented. Some women may want to consider a caesarean section.

The British Association for Perinatal Medicine (BAPM) framework for palliative care can be found here: https://www.bapm.org/resources/palliative-care-in-perinatal-medicine-framework

Location of neonatal units linked into hospices can be found here: https://ndau-maps.github.io/UnitMap2020/

ii. T21

Parents continuing after a diagnosis of T21 may want to have their 20-week screening scan performed by a fetal medicine specialist to check for cardiac and other physical findings that can be associated with the condition.

As there is increased risk of placental dysfunction, third trimester scans should be scheduled to monitor and discussions had with parents about elective induction before 40 weeks to reduce risk of stillbirth.

iii. T18 and T13

Antenatal parallel planning with an early involvement of neonatal and paediatric palliative care / hospice teams (where the facilities are available), is recommended. Continuity of care during the pregnancy, and ongoing support for example by a fetal medicine midwife, will be helpful to parents.

There will need to be sensitive and open documented discussions about how the birth will be managed including what kind of interventions may be appropriate.

iv. Spina bifida

The involvement of paediatric neurologists and/or neurosurgeons alongside the fetal medicine team will be important in helping to give parents as much information as possible about the implications of the diagnosis in their individual case. It will also be important to discuss any interventions they might want to consider.

MRI may help add information to what is detected by ultrasound and be helpful in ascertaining whether in utero fetal surgery could be an option. More information about the NHS fetal surgery service for open spina bifida can be found here: https://www.uclh.nhs.uk/our-services/find-service/womens-health-1/maternity-services/your-pregnancy/spina-bifida-open-fetal-surgery

v. Cleft lip and palate

It will be important to establish as far as possible through expert fetal medicine scanning that the cleft lip is an isolated finding. It is also the case that it can be difficult to diagnose cleft palate on scan. Some parents may choose to have amniocentesis to see if there is an associated genetic or chromosomal condition.

Referral should be made to the local cleft lip and palate team for information on what to expect postnatally, e.g. feeding, surgical management and longer term follow-up https://www.clapa.com/treatment/nhs-cleft-teams/#contact

vi. Congenital diaphragmatic hernia (CDH)

The outlook for babies with CDH can vary and parents will need information and counselling from an MDT including neonatologists and paediatric/neonatal surgeons. MRI may be helpful in establishing the effect on lung development and fetal echocardiogram should be offered.

In some cases it may be appropriate to discuss the possibility of undergoing the FETO procedure at a specialist unit. The charity CDH UK provide parent friendly information on this: https://cdhuk.org.uk/the-journey-of-a-little-balloon/

Fetal growth should be monitored and a plan for timing and place of birth agreed. Place of birth will need to be a level 3 neonatal unit linked to a paediatric surgical centre.

vii. Gastroschisis and exomphalos

As well as fetal medicine, parents will benefit from information and counselling from the neonatal team and neonatal/paediatric surgeons. Outlook with exomphalos will depend on severity and whether it is isolated. Fetal growth should be monitored, and sometimes provision of computerised fetal heart rate analysis (cCTG) from 32 weeks may be appropriate. This should help inform a plan for timing of birth - which should take place in a level 3 neonatal unit linked to a paediatric surgical centre.

viii. Congenital heart disease

Cardiac conditions detected antenatally vary from those that can resolve or are easily corrected to severe cases requiring complex intervention after birth or perhaps only palliative care. Most often care will involve fetal/paediatric cardiologists and neonatal teams who will discuss and agree an individualised pathway and determine timing and place for the birth.

Variants that are reported if seen at the 20-week screening scan:

These are four variants detected at the 20-week screening scan (each seen in approximately 1% of pregnancies). Any finding that may indicate an issue in the pregnancy is likely to cause anxiety for parents. They will need clear information about what conditions the variants could indicate as well as the chance of their being completely benign.

In all cases a referral should be made to fetal medicine to confirm the finding and check for any other signs that there may be an underlying issue.

Increased nuchal fold

A nuchal fold of 6mm or over seen at the 20-week screening scan should be reported to parents as, while often it is simply a naturally occurring variant, sometimes it can indicate a chromosomal/ genetic condition, a cardiac issue or a condition that may lead to hydrops. A follow up scan should be scheduled with fetal medicine specialists to confirm the finding and rule out other findings that may point to a genetic condition.

Ventriculomegaly

Ventriculomegaly is used to describe the circumstance of the distal lateral ventricles measuring above 10mm. It is usually detected at the 20-week screening scan, but will sometimes only become apparent in the third trimester. Because this is a finding in the fetal brain, the anxiety it can cause expectant parents should not be underestimated. Parents will need referral to fetal medicine and careful counselling about the possible causes and the chances of a good outcome if it is below 15mm and confirmed as isolated.

Renal pelvic dilatation (RPD)

While NHS FASP uses a threshold of 7mm for RPD, it is recognised that some hospitals will have a different (most often lower threshold) for reporting and/or antenatal or neonatal follow-up, particularly in a pregnancy that may have already been identified as being at a higher risk of a chromosomal condition. As an isolated finding, in a pregnancy previously screened as lower chance for chromosomal conditions, RPD does not appear to significantly increase the chance of a chromosomal condition. Where hospitals have a different threshold it is important that their rationale for doing so is explained to parents.

Echogenic bowel

It can be helpful for parents to know that most often echogenic bowel in isolation does not indicate any issue with the baby's development and its cause is unexplained or sometimes due to early pregnancy bleeding. However, because of the possible associations with disorders of placental function, infections, cystic fibrosis and chromosomal conditions further testing or fetal surveillance is likely to be offered. A referral to fetal medicine will be needed as other findings will inform exactly which tests are offered and ongoing care.

6. Termination of pregnancy

Once expectant parents decide to terminate their pregnancy, a co-ordinated care plan should be put in place.

If there is no confirmed genetic diagnosis and the clinical team believe detailed post mortem investigations could provide useful information about cause or recurrence risk this should be sensitively discussed with parents as it may affect choice of termination method. The conversation should be documented and parents' wishes respected.

Choice of termination method

Parents will need to know that they have a choice of termination method (unless medically contraindicated) between medical and surgical management. While most NHS hospitals are limited in their in-house expertise to offer surgical management, particularly dilatation and evacuation (D&E), this is often available until 23^{+6} weeks' gestation through independent service providers (under NHS contract). There are also a number of NHS centres providing a specialised surgical termination of pregnancy service for women who for medical reasons cannot be treated in an independent clinic: https://www.england.nhs.uk/wp-content/uploads/2021/03/1834-Service-Specification-final.pdf

There is no evidence to suggest one method is better than another in terms of physical or psychological recovery, but we know choice of method is important to parents.

***Key point:** Parents will need clear explanation of what both methods involve and the potential benefits and risks in their particular situation, in order to work out which best fits their individual circumstances and coping style.*

Medical termination of pregnancy

Parents will need clear and sensitively communicated information about the process. This will include explaining the function of medications. Firstly, the administration of mifepristone and then on admission, misoprostol, according to local guidance. Special considerations may need to be taken with the dosage of misoprostol with advancing gestation and in women presenting with previous uterine surgery for example caesarean section or myomectomy.

They will need to know that even at early gestations pain levels can be high and the choices of pain relief they may have. This choice may be dictated by where they will have their termination. If possible, they should be given a choice of location as some parents will value the opportunity to have midwifery led care on the maternity ward, while others will prefer to be well away from the labour ward and women giving birth in different circumstances.

Parents will make different decisions about seeing and holding their baby (they will need to know how their baby might look) and memory making so they should be talked through their options without pressure. Some will value the opportunity to discuss and agree a plan. Women need to know that in approximately 5% of cases, they will need to have the placenta surgically removed after giving birth.

The possibility of a baby showing signs of life will need to be discussed, and what this will mean in terms of registering the baby and coronial involvement.

From 21^{+6} weeks' gestation, the RCOG recommend feticide is offered to ensure the baby is not born alive. https://www.rcog.org.uk/media/ny1pc5ml/position-statement-coroners-guidance-no-45.pdf (December 2023)

When parents are facing termination in the third trimester there may be some, having been counselled about the risks and implications, who decide to deliver by caesarean section.

***Key point:** Wherever the medical termination takes place, parents should be in a private room that can accommodate a partner or support person and follow up care must be consistent.*

Surgical termination of pregnancy

The two surgical methods of termination are vacuum aspiration (up to 15^{+0} weeks) and dilatation and evacuation (D&E) from 15^{+0} weeks to 23^{+6} weeks. Parents will need to know what the procedure involves as well as what to expect physically afterwards. Importantly, it will need to be gently explained that the baby is not removed intact so they will not have the opportunity to see and hold the baby.

Fetal remains after a surgical termination will not be suitable for full post mortem, but genetic testing can be done. The latter will need to be planned and organised before a procedure in the independent sector.

Most NHS hospital settings can only provide vacuum aspiration up until 13^{+0} weeks' gestation. However, independent sector clinics (bpas, MSI Choices, NUPAS) can offer D&E under NHS contract until 23^{+6} weeks. Some parents will be distressed at the prospect of attending a standalone clinic away from the hospital for their procedure (where there will be women terminating unwanted pregnancies) but many will tolerate this in order to avoid labour and birth. Most will prefer to be given general anaesthetic to prevent being aware of what is happening, but some may consider conscious sedation. However, conscious sedation does not guarantee no recall.

Memory making in the context of surgical termination is more limited. However, parents can be offered scan pictures and some BPAS clinics will provide footprints if requested. There will need to be a discussion pre-procedure about what parents want to happen with their baby's remains.

If parents opt to use the independent sector, this should not affect their continuity of care and follow up by NHS professionals. It will be helpful if links can be made between NHS hospital and independent provider clinic to facilitate this.

https://www.nbcpathway.org.uk/pathways/termination-of-pregnancy-for-fetal-anomaly-topfa-bereavement-care-pathway/

See appendix B for information checklist for discussions on surgical and medical procedures.

7. Postnatal follow up after loss

Physical recovery

Before being discharged after a loss, parents should be made aware of what to expect from the physical recovery and know who to contact with any concerns. This discussion will include post procedure pain, signs of infection, bleeding and lactation.

A follow up appointment with a specialist healthcare professional should be scheduled around six weeks post loss. It can be helpful, if possible, if this appointment is held in a location away from the antenatal clinic as many parents will find it distressing to be in an environment with expectant parents. Discussions should include who to contact should they find themselves pregnant again and what might happen.

Psychological support

The early days after a loss can be difficult for bereaved parents. After initial relief that the physical part is over, they can be hit by a wave of complex emotions. While this may be normal in the circumstances, some parents describe feeling overwhelmed and will benefit from support and reassurance that their reaction is to be expected.

Parents bereaved after termination can feel particularly isolated as they may not disclose their circumstances to many as they fear judgement. Ideally, a bereavement midwife should be involved in following up parents and community services should be informed.

If there is no bereavement support available through the hospital (and if this is the case this should be addressed) then staff must ensure that parents are given information about where to access help. See appendix for organisations parents may find helpful.

***Key point:** All parents who have experienced loss after antenatal diagnosis must be offered bereavement support.*

Postnatal investigations

If parents consent to post-natal investigations, they will need to know when they can expect results and how they will receive them. The wait for results from genomic sequencing can be lengthy and the distress this may cause should be acknowledged.

Long delays in receiving postnatal testing results can be particularly difficult for those parents who do not want to delay trying to conceive again. If appropriate, it will be helpful for them to know that they do not have to wait unless there are compelling medical reasons to do so.

8. Subsequent pregnancies

Whatever the outcome after a prenatal diagnosis for parents, we can generalise that any subsequent pregnancy is likely to be anxiety laden and that they will benefit from sensitive individualised care. Pregnancy has changed forever as they are no longer naive to the possibility of all not progressing as expected. There is likely to be extra distress if the diagnosis resulted in a loss. Even if there is a very low chance of recurrence, this is not going to completely reassure most bereaved parents. They will appreciate co-ordinated care where staff are aware of their previous experience and accommodate their needs where practicable.

If they were looked after well, many parents will value receiving care in a subsequent pregnancy from members of the team involved in their difficult experience. Others may prefer to book at another hospital (if feasible) in a next pregnancy, so they do not have to revisit the location of their previous experience.

If the previous diagnosis was understood to be a 'random' event and unlikely to recur, it can be tempting for professionals to think that parents may be reassured by being classified as 'low risk' and offered standard care. Although it is important to listen to parents and take the lead from them, most will appreciate discussing ways of managing their inevitable anxieties and an acknowledgement that such anxieties are inevitable. This may include extra ultrasound scans, having the 20-week screening scan performed by fetal medicine and if the diagnosis was T21, T18 or T13, being offered NIPT as a first-tier screening test.

9. Maintaining high-quality care

Staff training and support

Caring for parents who are often highly anxious or distressed due to news about their baby's development can be challenging. It can make demands on staff on a personal as well as professional level. This is heightened in the context of the current NHS, with staff shortages and limited resources putting extra pressure on healthcare professionals.

In order to provide the quality of care parents deserve it is crucial that staff are as well-equipped as they can be. Training in sensitive communication skills, delivering unexpected and difficult news and dealing with distress and grief should be available to all staff who interact with parents. There should also be provision of support for staff.

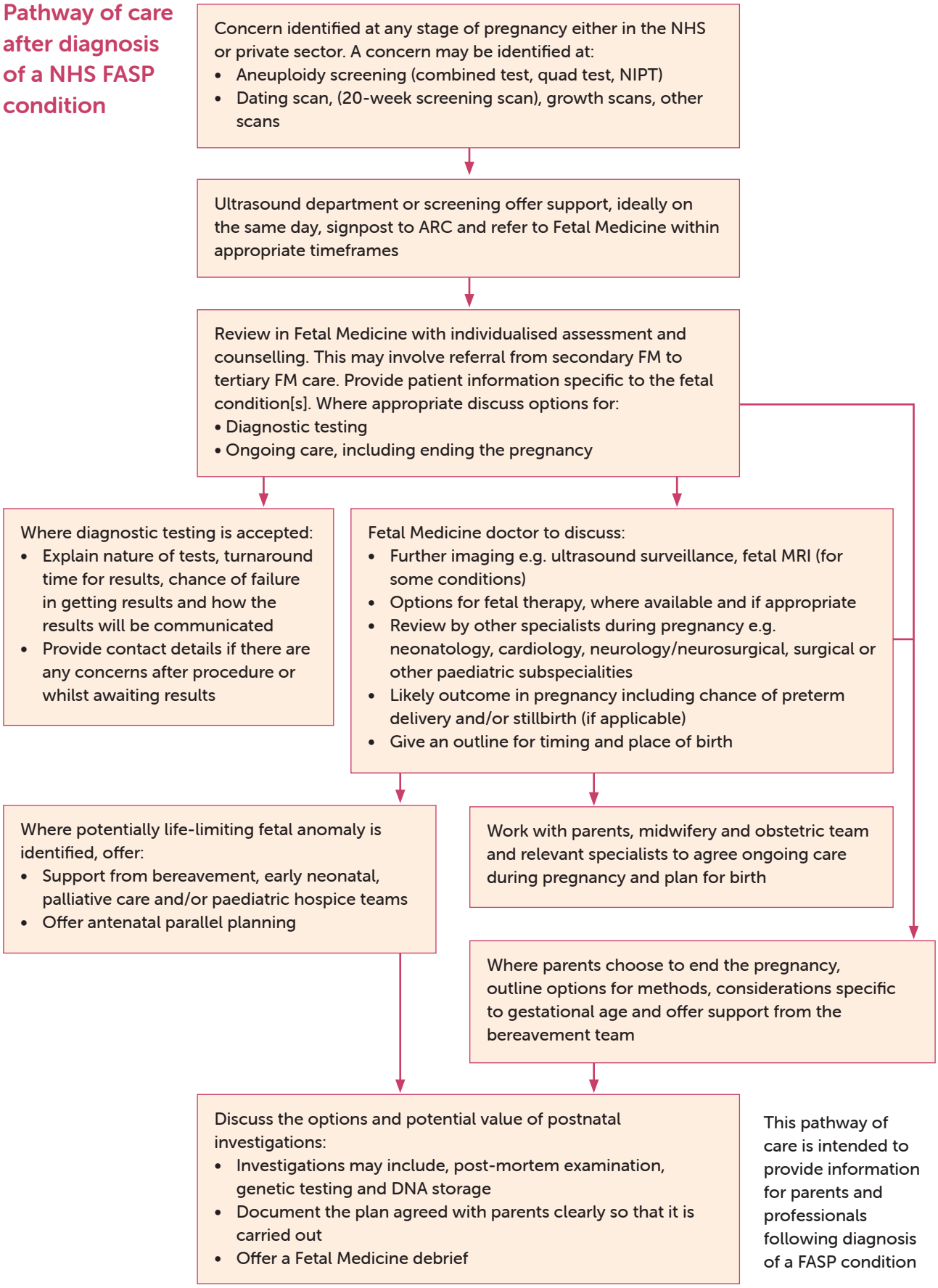
Audit and review

All units should be included in reviewing parent care through antenatal diagnosis to maintain consistency and facilitate improvement. Parents should have the opportunity to provide feedback but not be pressured to do so. In the appendix there is an example of a parent questionnaire to provide feedback on fetal medicine appointments. This can be tailored to local requirements and translated if necessary.

10. Appendices

A. Care Pathway Flowchart

Pathway of care after diagnosis of a NHS FASP condition



This pathway of care is intended to provide information for parents and professionals following diagnosis of a FASP condition

B. Method of termination - essential information

Specific to surgical termination

- Discussion of how the procedure is carried out under general anaesthetic, including sensitively explaining that the baby will not remain intact, i.e. there will be no baby to see or hold afterwards.
- Where it will take place – NHS gynaecology ward, day surgery unit or (under NHS contract) independent provider clinic run by BPAS, MSI Choices or NUPAS (BPAS have specific pathway and client literature)
- Preparation for surgery - need for cervical preparation on the day or day before. If day before, what to do if labour starts.
- Risk of complications – including retained tissue, haemorrhage
- There will not be the possibility of a full post mortem – but genetic testing can be done, requiring liaison with provider of surgical termination.
- Whether partner/supporter will be able to accompany woman and for what parts of process
- Preparation for the likelihood of being around women ending unwanted pregnancies or undergoing other types of procedures
- Physical recovery, including lactation, pain and discomfort afterwards – how long bleeding might last. What to look out for.
- Memory making: possibility of obtaining scan pictures (BPAS can sometime offer hand and footprints)
- What happens to remains – some women may wish to take them away, have funeral directors involved etc.
- Ensure continuity and follow up arranged if procedure taking place in the independent sector.

Surgical termination providers

NHS England Specialised Surgical Termination Service https://www.england.nhs.uk/wp-content/uploads/2021/03/1834-Service-Specification-final.pdf

Independent sector providers (ISPs) contracted by NHS

BPAS www.bpas.org

MSI Reproductive Choices https://www.msichoices.org.uk/

NUPAS https://www.nupas.co.uk/

Checklist for NHS staff when referring into ISP:

- BPAS provide a specific referral form on the page: https://www.bpas.org/make-a-referral/
- Ensure to give full medical history, gestation and placental site, also Hb, RH status, BMI. It is important to confirm woman is suitable for treatment at ISP
- Inform if testing required so this can be organised in advance
- Check options for fetal remains
- Discuss availability of memory making should parents wish (BPAS can offer footprints)
- Assurance that ISP offer safe quality assured surgical termination care
- Management of expectations around being in vicinity of women ending unwanted pregnancies, that contraception may be discussed etc

Specific to medically induced labour

- Discussion of the procedure including the use of mifepristone (what it is used for and why) and that admission later (the interval may vary). Explanation of how prostaglandins will then be used to induce the labour.

- Risk of complications – including the possibility of a retained placenta (5% of women will need surgical removal, haemorrhage etc.)

- Ensuring woman is aware that she will experience labour and painful contractions and that it is difficult to estimate duration. An overnight stay will usually be involved.

- Pain relief options (and possible accompanying side-effects).

- Explanation that when the baby is about to come it can feel like a bowel movement is imminent

- Where termination will take place – gynaecology or labour ward? Will there be a private room that can also accommodate partner/support person?

- If on gynaecological ward, explain type of care to expect, possible limitations on pain relief etc

- If on labour ward, discussion about possible proximity to other women who are having healthy babies.

- Physical recovery, including lactation, pain and discomfort afterwards – how long bleeding will typically last. What to look out for.

- The possibility of the baby being born showing signs of life and the implications of this (registration of birth/death, informing of coroner, maternity rights)

- If ≥ 22 weeks gestation, discuss offer of feticide, explain why this is done, where it will happen and what is involved

- What the baby might look like - the option of seeing and/or holding the baby, taking photographs and asking for other keepsakes. NB This should be presented as an individual choice as there is no conclusive evidence to suggest that seeing or not seeing the baby aids emotional recovery.

- If appropriate, woman/couple might want to consider making a 'birth plan' to cover some of the above and things like 'skin to skin', cutting the cord/washing baby etc

C. Example feedback questionnaire

Patient questionnaire - Your fetal medicine appointment

Please help us to improve our service by taking a few minutes to tell us about your visit to the fetal medicine unit today. We want to make sure you have a good understanding of the information we have given you and to find out if you felt you were involved in decisions about your pregnancy care.

We know appointments in our fetal medicine unit can bring distressing or worrying news. But we would be very grateful for your feedback as it will help us to provide the highest quality care to our patients.

Your answers will be kept anonymous and nothing you say will affect the care you receive.

Date .....

Who was your appointment with today?

.....

1. Before I arrived, I had a good understanding of the reason for my fetal medicine appointment today

- ○ Strongly agree
- ○ Agree
- ○ Neither agree nor disagree
- ○ Disagree
- ○ Strongly disagree

2. At my appointment today, staff explained things to me about my pregnancy in a way I could understand

- O Strongly agree
- O Agree
- O Neither agree nor disagree
- O Disagree
- O Strongly disagree

3. At my appointment today, I felt able to ask questions about my pregnancy

- O Strongly agree
- O Agree
- O Neither agree nor disagree
- O Disagree
- O Strongly disagree

4. At my appointment today, I was involved as much as I wanted to be in decisions about what happens next

- O Strongly agree
- O Agree
- O Neither agree nor disagree
- O Disagree
- O Strongly disagree

5. At my appointment today, staff were sensitive to my concerns about my pregnancy

- ○ Strongly agree
- ○ Agree
- ○ Neither agree nor disagree
- ○ Disagree
- ○ Strongly disagree

6. After my appointment today, I have a good understanding of the next steps in my care

- ○ Strongly agree
- ○ Agree
- ○ Neither agree nor disagree
- ○ Disagree
- ○ Strongly disagree

If you have any other comments you would like to make about your fetal medicine appointment today please add these in the box below:

Your responses to this questionnaire will be kept anonymous, but if you do want to discuss your answers please write your name in the box below and x will contact you.

Thank you for taking the time to complete this questionnaire

D. List of support organisations for signposting

ANTENATAL RESULTS AND CHOICES (ARC)

Antenatal Results and Choices offer impartial information and support to parents through antenatal screening and its consequences. ARC provides specialised bereavement care to those who have termination after a prenatal diagnosis.
https://www.arc-uk.org/

BLISS

Bliss supports parents whose baby/babies are born early.
https://www.bliss.org.uk

CDH UK - The Congenital Diaphragmatic Hernia Support Charity

CDH UK offers information and advice to parents around congenital diaphragmatic hernia (CDH)
https://cdhuk.org.uk/

CLAPA

The Cleft Lip and Palate Association (CLAPA) supports people affected by cleft lip and palate.
https://www.clapa.com/

DOWN'S SYNDROME ASSOCIATION (DSA)

The Down's Syndrome Association supports people who have Down's syndrome, and their parents and carers, throughout their lives.
https://www.downs-syndrome.org.uk/

INFOKID

infoKID provides information for parents and carers about kidney conditions in babies, children and young people.
https://www.infokid.org.uk/

LITTLE HEARTS MATTER

Little Hearts Matter is a UK-wide charity offering help to anyone affected by the diagnosis of single ventricle heart condition.
https://www.lhm.org.uk/

REACH

Reach supports children and families affected by upper limb differences
https://www.reach.org.uk

SANDS

Sands provides support to anyone affected by the death of a baby, before, during or shortly after birth.
https://www.sands.org.uk/

SHINE

Shine provides specialist advice and support for spina bifida and hydrocephalus across England, Wales and Northern Ireland.
https://www.shinecharity.org.uk/

SOFT UK

SOFT UK provides support and information to all those who are affected by Patau's syndrome (Trisomy 13) or Edwards' syndrome (Trisomy 18) and their related disorders.
https://www.soft.org.uk/

STEPS

Steps supports those affected by childhood lower limb conditions.
https://www.stepsworldwide.org/

TINY TICKERS

Tiny Tickers provides information and support for parents of babies with serious heart conditions.
https://www.tinytickers.org

TOGETHER FOR SHORT LIVES

Together for Short Lives is the UK's leading charity for Children's Palliative Care.
https://www.togetherforshortlives.org.uk/

TOMMY'S

Information and support around baby loss.
https://www.tommys.org/baby-loss-support

TWINS TRUST

Twins Trust provides information and support for families with twins or multiples.
https://twinstrust.org/

UNIQUE

Unique provides support and information to anyone affected by a rare chromosome disorder or an autosomal dominant single gene disorder and works with any interested professionals.
https://rarechromo.org/

E. Staff Training Resources

https://www.e-lfh.org.uk/programmes/nhs-screening-programmes/

https://www.genomicseducation.hee.nhs.uk/genotes/fetal-and-womens-health/

Training and events – Antenatal Results and Choices (ARC) (**www.arc-uk.org**)

https://www.nbcpathway.org.uk/learning-resources/

For Royal College of Midwives members:
https://www.rcm.org.uk/promoting/education-hub/i-learn-and-i-folio/

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Group members:
Chair: Jane Fisher
Secretariat: Jenny Price

Siobhan Alt
Rebecca Al Ausi
Rita Arya
Denise Barnes
Andy Breeze
Lauren Capacchione
Emma Ferriman
Hilary Goodman
Gill Harrison
Mark Kilby
Teresa Lardner
Surabhi Nanda
Kate Navaratnam
Alison O'Brien
Nadia Permalloo
Roxanne Sicklen
Junaid Rafi
Linden Stocker
Dagmar Tapon
Amy Wood
Angela Yulia

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GOV. UK (2008) Human Fertilisation and Embryology Act 1990 amended 2008
https://www.legislation.gov.uk/ukpga/2008/22/contents

NICE quality standard (2021) Abortion care. This quality standard covers care for women of any age who request an abortion. It describes high-quality care in priority areas for improvement Overview | Abortion care | Quality standards | NICE

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