Frequently Asked Questions for patients – Open pre-natal surgery for open spina bifida service

1. What happens after I am referred for open fetal surgery for spina bifida?
After your referral is received by the Fetal Surgery Centres, they will call you for an initial telephone consultation within 48 hours. During this telephone consultation, the fetal surgery co-ordinator(s) will confirm your contact details and ask you about your previous medical history. You will have the opportunity to discuss your baby’s spina bifida diagnosis. They will tell you about the option of open fetal surgery, the risk and benefits of fetal surgery and you will be able to ask questions. If you are interested, and eligible, the Fetal Surgery Co-ordinator will arrange for you to come to a Fetal Surgery Centre for a further face-to-face consultation. If there are obvious reasons why you would not be eligible for surgery, then these will be explained to you and it will be recommended that you do not attend the Fetal Surgery Centre for any further assessments.

2. If I am eligible for fetal surgery where will my consultation take place?
There are two Fetal Surgery Centres which are commissioned by NHS England. Your consultation will take place either in University College London Hospital (UCLH), London or in University Hospitals (Universitaire Ziekenhuizen (UZ), Leuven, Belgium. You will be referred to one of these hospitals depending the location of the referring English Regional Fetal Medicine Unit (RFMU) which is linked to your local maternity unit. Recognised travel routes for patients have also been taken into account. The date for your consultation will be within one to two weeks of your referral and telephone consultation or adjusted to the scheduled day of surgery. The timing will depend on how far along you are in your pregnancy and the day the surgery would take place.

3. Where can I find more information?
The Antenatal Results and Choices website (ARC, www.arc-uk.org) is a good source of information for anyone who has had an unexpected result in pregnancy.

The Spina bifida and Hydrocephalus Information, Networking, Equality website (SHINE, www.shinecharity.org.uk) has more information specifically about spina bifida.

The UCLH fetal surgery website (www.uclh.nhs.uk/spinabifida-fetalsurgery) has a short video about spina bifida and the fetal surgery service. It contains links to the service’s patient information leaflet about open fetal surgery for spina bifida. The website also has information on the MOMS clinical trial which provided the evidence to support fetal surgery, and research publications of the joint London and Leuven teams.

4. Do I need an amniocentesis before my assessment?
To be eligible for open fetal surgery, you will need to have a normal genetic testing result of your baby. Genetic testing of your baby involves having a prenatal diagnosis test such as chorionic villus sampling (CVS) or amniocentesis. This is different from
the so-called non-invasive prenatal test on the mother’s blood, which screens for Down’s, Edward’s and Patau’s syndromes (also known as trisomy 21, 18, 13).

The result of these prenatal diagnosis genetic tests can take up to three weeks to arrive. The doctors who refer you to the Fetal Surgery Centre will probably recommend that you have the testing before your consultation at the Fetal Surgery Centre as this will give time for the result to be available when you are assessed. However, due to timing, if it is not possible to do such a test before you come to the Fetal Surgery Centre, the test can be done at your referring Fetal Medicine Unit afterwards as long as there is still time. The NHS commissioning does not fund invasive testing at the Fetal Surgery Centres.

5. What happens if I am referred to the UCLH or Leuven Fetal Surgery Centre for my consultation?

On arrival you will meet several team members, including, one or more fetal medicine specialists and a radiologist who is specialised in ultrasound and MRI scanning for this condition. According to your needs, other specialists may be involved. Even if you have had scans before referral, the fetal surgery team will repeat these to have a very detailed review of your baby and to look for some conditions relevant to the surgery. Please see below for how the assessments will take place and see Appendix A for travel and accommodation information for you and your partner.

5.1 UCLH, London, United Kingdom – assessment process

Your assessment will usually take place either on a Monday or a Tuesday.

The specialised ultrasound will take place in the Fetal Medicine Unit (FMU) at UCLH. Please arrive 15 mins prior to your appointment.

The Fetal Medicine Unit (FMU) is located:
1st floor, Elizabeth Garrett Anderson (EGA) Wing, University College London Hospital (UCLH), 25 Grafton Way, Fitzrovia
London WC1E 6DB

The EGA wing is a small hospital wing at the back of the main UCLH site (please see the map below). It is best to enter this wing via the entrance on Grafton Way, although you can walk through the main building and out across the ambulance car park.

The Fetal MRI will take place in the Radiology Department. This is in the main UCLH hospital building and not in the EGA wing. We would advise you to avoid sugary or caffeinated drinks for an hour before your scan to reduce excessive fetal movement. Please arrive 30 minutes before your appointment to allow time for preparation and answer a safety check list. The MRI scan takes place at the following location:
MRI reception, Radiology/Imaging Department
Level 2, University College Hospital
235 Euston Road, London NW1 2BU
5.2 University Hospitals Leuven, Belgium – assessment process

Assessments usually take place on a Friday or a Monday. Please plan to arrive in good time, ideally at least one hour prior to your scheduled appointment to the main entry of the hospital to register as a patient and then to walk to the correct department.

Main Entrance
University Hospitals Leuven, campus “Gasthuisberg”
Herenstraat 49
3000 Leuven

From there you will receive instructions on a colour coded map where to go on the campus.

The specialised ultrasound will take place in the Fetal Medicine Unit, Woman and Child Hospital, Colour Code “Red”, Level 1, Unit 499, which is the Outpatients of Obstetrics and Gynaecology (please see the campus map below).

The specialised fetal MRI will take place in the Radiology Department. We would advise you to avoid sugary or caffeinated drinks for an hour before your scan, to reduce excessive fetal movements. Please arrive 30 minutes before your appointment to allow time for preparation for the scan and answer a safety check list.

The MRI scan takes place on the same campus, at the following location: MRI unit, unit 600 (follow the blue arrows).

If I am asked to come for assessment, who can I bring with me?
If travelling to either hospital, the woman can be accompanied by one partner or carer for her assessment appointment and any inpatient stay for surgery.

If the woman is travelling to Leuven for assessment and surgery, one partner or carer may accompany her. If the woman has children, a feeding babe in arms only may accompany the woman given that if she undergoes surgery, she will require high dependency care and will need to recover. No other child(ren) should accompany the woman and her partner/carer and alternative childcare arrangements should be made for the case of these, if any exist.

6. When will I have my counselling regarding fetal surgery?
Your counselling for open fetal surgery will take place on the same day as your assessment and it will take place in the FMU department in both Fetal Surgery Centres. The counselling will take into account the information from the ultrasound imaging and potentially other results from genetic testing and the previous MRI scan.
As the fetal MRI results may not always be available at the time of counselling, they may need to be communicated to the Fetal Surgery Unit later on.

7. Contact details:
Spinabifida-fetalsurgery@nhs.net
This email address connects to both centres, and your question will be dealt with by the Fetal Surgery Centre which is in managing the care of patients from your referral area.

Website from the highly specialised services for fetal surgery:
www.uclh.nhs.uk/spinabifida-fetalsurgery
Appendix A - How do I get to the Fetal Surgery Centres?

A.1 How do I get to the University College London Hospital, UK?

We recommend that you travel to UCLH by public transport. There are no allocated parking facilities at the hospital.

**By train**

The closest rail stations are St Pancras/ Kings Cross station and Euston station. Euston station is a five to ten minute walk from UCLH. Kings Cross/ St Pancras station is a 15 to 20 minute walk from UCLH; this journey can also be done by bus or underground.

**By bus**

- Tottenham Court Road - Northbound (Warren Street station) - no’s 10, 73, 24, 29, 134
- Gower Street - Southbound (University Street) - no’s 10, 24, 29, 73, 134
- Euston Road - no’s 18, 27, 30, 88

**By underground (tube)**

Warren Street (Northern / Victoria Lines) and Euston Square (Circle / Hammersmith & City / Metropolitan Lines) are both located within a five minute walk of the UCLH. For further travel information please go to [Transport for London](https://tfl.gov.uk).

**By car**

If you choose to drive to your appointment at UCLH, please note that UCLH is within the London Congestion Charge zone. For details of how to pay, contact Congestion Charging at Transport for London on 0845 900 1234. Car parking on
the streets around UCLH is extremely limited. Private car parks, such as NCP (https://www.ncp.co.uk) can be found near Euston and Kings Cross.

### Notes for patients attending UCLH:

You can be accompanied by one partner or carer for the duration of your stay. If you have children, you may take a feeding babe in arms only given that you may undergo fetal surgery, will require high dependency care and will need to recover. Alternative childcare arrangements should be made for any other children.

The referring clinical team will liaise with the UCLH Fetal Surgery Centre team to confirm the accommodation arrangements in London for you and your partner/carer, which will include:

a. You will be admitted to the hospital the day before surgery. If it is agreed with the London Fetal Surgery Centre team that you can arrive one or two days prior to this e.g due to distance travelled, and can be accommodated in the hospital's family accommodation, you will be allocated a bed, or, if there are no family accommodation beds available in the unit, the referring team will book and pay for one room for you and your partner/carer in a reasonably priced hotel nearby (maximum £150 per night). All patients will be provided with food once they are admitted to a hospital bed and for the duration of their stay.

b. Your partner/carer will also be accommodated in the hospital's family accommodation if there is space available. If not available, bed and breakfast in a reasonably priced hotel can be booked by the referring unit to a maximum cost of £150 per night at no cost to you/your partner. No other food will be refunded.

You will be liable to pay for any damage you/your partner cause to the family or hotel accommodation.

NHS England will not fund any travel costs for you and your partner to travel to the UCLH Fetal Surgery Centre to access the service. This will be your responsibility to fund, however eligible patients can access reimbursement for travel costs via the Hospital Costs Travel Scheme. If you qualify, the referring hospital will reimburse you the costs directly on submission of receipts.
A1.2 How do I get to the University Hospitals Leuven, Belgium?

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<th>University Hospitals Leuven, Belgium</th>
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<tr>
<td>University Hospitals Leuven, (Universitaire Ziekenhuizen) (UZL) campus “Gasthuisberg”</td>
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<tr>
<td>Herestraat 49</td>
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<td>3000 Leuven</td>
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<td>Directions:</td>
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**Leuven** is close to Brussels, which can be reached by aeroplane (Brussels National Airport at Zaventem) or by train (Eurostar to Brussels Zuid/Midi station).

**Airport and taxi or train to Leuven:**
The nearest airport to the hospital is Brussels International Airport (Zaventem). From the airport in Brussels there is an easy train connection to Leuven – the trains run every half hour and the travel time is approximately 15 minutes. Leuven railway station is located 4 km from the hospital. You can also take a taxi direct from the airport to the hospital, the cost will be approx 90- 100 Euro.

**Main train lines and station:**
Leuven is served by many trains traveling from Brussels, eastbound calling for Liège/Hasselt/Genk and other cities, as well as from Antwerp, Mechelen, and other cities in Belgium. The Leuven railway station is located 4 km from the hospital. Taxis and buses are available at Leuven train station.

**By bus from the railway station:**
The bus station is on the right when exiting the railway station towards the city center. Busses operated by “De Lijn” directly to campus Gasthuisberg ([Line 600: “Buitenringbus”](https://www.uzleuven.be/en/directions-to-campus-gasthuisberg)) on platform 12 depart every 20 minutes. It takes less than 10 min and stops in front of the hospital. Many other bus lines go that direction as well, e.g. line 317 (platform 10, direction of Kraainem). There is a bus stop in front of the main entrance of the hospital. There is a shop for buying tickets at the bus station (called “De Lijn shop”), yet only open during office hours.

**By taxi from the railway station:**
You can take a taxi from the railway station; the cost will be less than 15Euro(€).

**Notes for patients attending UZ Leuven:**
You can be accompanied by one partner or carer in Leuven for the duration of your stay. If you have children, you may take a feeding babe in arms only given that you may undergo fetal surgery, will require high dependency care and will need to recover. Alternative childcare arrangements should be made for any other children.

The referring clinical team will liaise with the UZ Leuven Fetal Surgery Centre team.
to confirm the accommodation arrangements in Belgium for you and your partner/carer, which will include:

a. You will be admitted to the hospital the day before surgery. If it is agreed with the UZ Leuven Fetal Surgery Centre team that you can arrive one or two days prior to this e.g. due to distance travelled, and can be accommodated in the hospital’s family accommodation, you will be allocated a bed in a single room in the hospital’s 16-bed family accommodation, or, if there are no family accommodation beds available in the unit, the referring team will book and pay for one room for you and your partner/carer in a reasonably priced hotel nearby which has been determined as £120.00 per night, (there are a number of local hotels which are about a 15 minute walk or 5 minute drive/taxi ride away). Once admitted as an inpatient, all food will be provided to you.

b. Your partner/carer will also be accommodated in the hospital’s family accommodation in a single room if there is space available. If not available, a room in a reasonably priced hotel will be booked by the referring unit in a bed and breakfast basis only. No other food costs will be paid for. You will be liable to pay for any damage you/your partner cause to the family or hotel accommodation.

You will not have to fund outward and return travel costs between your family home and UZ Leuven hospital, including flights or ferry or train/Eurostar to and from Brussels airport and onward train travel to Leuven in Belgium for the woman and her partner/carer as NHS England will fund reasonably priced travel costs between the family’s accommodation and the UZ Leuven hospital. The referring team will make and pay for the travel bookings at no cost to you.

Any transport between the hospital and the hotel, if one is required, will be refunded to you. Please keep receipts and present to you local referring unit on your return or if you wish to hire a car during the treatment period, you will be refunded the cost of a Group A car and the cost of fuel between the airport and the accommodation and between the accommodation and the hospital by your local referring unit.

NHS England will fund travel insurance for the you (for any circumstances not related to the pregnancy) and for your partner/carer. You should arrange the travel insurance for you and your partner/carer and will be reimbursed by the referring unit. The referring unit staff clinical should confirm that they have seen evidence of the insurance before they make your travel arrangements.

If you wish to hire a car during the treatment period, NHS England will fund a Group A car and the cost of fuel between the airport and the accommodation and between the accommodation and the hospital. The referring unit team will reimburse you on presentation of receipts. NHS England will not fund the cost of fuel for other journeys undertaken by the family.

You/Your partner will have to pay for all other daily living/subsistence costs such as food.