



An Independent voluntary support group for women with fibroids

www.femisa.org.uk

PRESS RELEASE

FOR IMMEDIATE RELEASE

FEMISA DEMANDS MULTI-DISCIPLINARY FIBROIDS CLINICS SO WOMEN ARE NO LONGER DENIED INFORMED CHOICE GYNAECOLOGISTS LACK KNOWLEDGE OF SAFER, LESS INVASIVE INTERVENTIONAL RADIOLOGY TREATMENTS

Motivated by a large number of complaints and enquiries from women saying *'I've been told by my gynaecologist that the only treatment for my fibroids is hysterectomy, but I don't want one. Are there any alternative?'* FEMISA carried out a Freedom of Information Survey in all English NHS acute hospital trusts.

The recommendations from NICE Heavy Menstrual Bleeding Clinical Guidelines [2007] state that women with symptomatic fibroids >3cm must be informed about and offered hysterectomy, uterine artery embolisation [UAE- see below] and myomectomy. Many are given no choice by gynaecologists.

The results of the FOI survey show –

- Only 44% of Trusts monitor patient information and choice by asking patients in surveys
- Only 45% of Trusts require an update of all care pathways to include latest NICE Guidelines
- NICE Guidelines recommend that women should be sent information before her out-patient appointment. Only 2 Trusts do this.
- 67% of hospital Trusts take no measures to ensure that women are made aware of their treatment options for fibroids and are offered choice.
- Only 3 hospitals stated that their gynaecologist received any training on UAE and that was informal training given by the local interventional radiologists. Gynaecologists therefore lack the knowledge to inform women about UAE or give them any advice as to whether they are suitable.

- Only 7 Trusts offer multidisciplinary fibroid clinics with gynaecologists working with interventional radiologists who carry out UAE, so that women are properly informed of all their treatment options.
- Where women have informed choice from a multi-disciplinary fibroid outpatient clinic e.g. Heartlands Hospital, UAE rates are significantly higher than the average i.e. many more women choose UAE in preference to hysterectomy.

FEmISA calls for –

1. All NHS Trusts and CCGs must have a policy to ensure that all patients are fully, properly and objectively informed about all their treatment options including risks. This must be audited at least annually in detailed patient questionnaires.
2. National patient information leaflets need to be developed by the relevant Royal Colleges and Medical Societies and importantly with the patient support groups and made available to all patients.
3. Multidisciplinary fibroid out-patient clinics with gynaecologists and interventional radiologists working together should be set up in all hospitals where in-patient fibroid treatment is offered to ensure that women are fully, objectively and properly informed about all their treatment options.
4. The Royal College of Obstetrics and Gynaecology needs to work with British Society of Interventional Radiology for the benefit of patients, including setting up training for gynaecologists on UAE, so they are better informed. Women patients must be the first priority and are not at the moment.

Ginette Camps-Walsh the co-ordinator and founder of FEmISA said ***“We founded FEmISA over 15 years ago, when UAE was comparatively new. We all wished to avoid hysterectomy and were delighted with the results of our embolisation treatment. We wanted to help other women have access to UAE. We did not think we would be here 15 years later still battling to ensure women are informed about UAE and given proper choice. It is absolutely shameful that hospitals and gynaecologist do not comply with Government Policies and NICE Guidelines. Women have to live with the consequences of their treatment.”***

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The full report - ***Patient Choice and Nice Compliance Survey on Fibroid Treatment*** can be found here –

<http://www.femisa.org.uk/images/femisa%20report%20on%20patient%20choice%20and%20nice%20compliance%209.17%20-%20final.pdf>

Some of the data in this report was included in the report from All Party Parliamentary Group on Women’s Health – ***Informed Choice? – Giving Women Control of their Healthcare***

<https://static1.squarespace.com/static/5757c9a92eeb8124fc5b9077/t/58d8ca34f7e0ab027a19247c/1490602579808/APPG+Womens+Health+March+2017+web+title.pdf>

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INFORMATION FOR EDITORS

Up to 80% of women have fibroids, the commonest benign tumours in the human body, found mainly in or around the uterus. Approximately 30% of women with fibroids have symptoms which require hospital treatment. There are approximately 64,500 diagnoses of fibroids in the NHS in England each year. Approximately 60% of the 46,000 hysterectomies performed in the NHS in England are for fibroids. Hysterectomy is one of the commonest treatments in the private sector after hip and joint replacement.

Fibroid Treatments

There are 4 in-patient treatments for fibroids >3cm² offered by gynaecologists – hysterectomy (surgical removal of the uterus [womb]) and myomectomy (surgical removal of the fibroid(s) alone). There are 2 less invasive treatments performed by Interventional Radiologists, uterine artery/fibroid embolisation [UAE/UFE] (the blood supply to the fibroids is cut off by introducing small particles via a small catheter[tube] inserted in the blood vessel) and magnetic resonance-guided focused ultrasound [MRgFUS] (high intensity ultrasound is guided by MRI to destroy fibroids – only available in a few hospitals). NICE clinical guidelines state that women with symptomatic fibroids >3cm must be informed about and offered hysterectomy, UAE and myomectomy. Many women are not.

UAE – fibroid embolisation is carried out by an interventional radiologist in an angiography suite. No general anaesthetic is required. The procedure normally takes 60-90 minutes and requires a 1-night hospital stay, with return to work in 1-2 weeks. Small particles are injected via a catheter [tube] into the uterine arteries supplying the fibroids. This blocks the blood supply to the fibroids and they die and shrink. The uterus is supplied with blood from the ovarian artery. There is no scar and women remain fertile and there have been many successful pregnancies after embolisation. UAE has been reviewed for safety and efficacy by NICE and found to be safe enough for use with normal hospital arrangements. There have been no deaths reported for many years. It is safer than hysterectomy or myomectomy and less expensive - <http://www.femisa.org.uk/index.php/cost-comparisons>

Hysterectomy – has never been formally reviewed for safety and efficacy, but has been used for approximately 150 years. It is removal of the uterus and other reproductive organs may be removed as well - cervix, part of vagina etc. It is an invasive operation that leaves women infertile and causes premature menopause. The mortality rate 0.6% 176 deaths within 90 days of the procedure. There are a number of approaches including abdominal the most invasive, vaginal and laparoscopic. The abdominal approach is normally used for fibroids.

Myomectomy – has never been formally reviewed for safety and efficacy and the mortality and overall morbidity rates are not fully known. The fibroid alone is surgically removed and fertility is maintained.

For more information see the FEmISA web site –
<http://www.femisa.org.uk/index.php/about-fibroids>