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One week to go to National Fertility Awareness Week

31 October - 4 November 2022

#Fighting4Fertility

National Fertility Awareness Week 31 October - 4 November 2022 is just one week away.

Make sure to catch these highlights, including a major, new survey revealing:

- the emotional impact of infertility and fertility treatment,
- the impact of juggling fertility treatment and employment, and
 - the crippling cost of IVF.

Gwenda Burns, chief executive of Fertility Network UK said: "Not being able to have the family you yearn for can be a traumatic and incredibly isolating experience. Far too often people struggle in silence with fertility issues but together - sharing stories and experiences - we can change perceptions, provide support and raise funds to help others. We are stronger together."

'National Fertility Awareness Week is a chance to challenge the taboos and myths around infertility and raise awareness of the devastating physical, emotional and social impact fertility problems wreak. This year the theme is #Fighting4Fertility because so much change is needed to help the 3.5million women and men in the UK facing infertility. Watch out for our major new survey assessing the impact of infertility and fertility treatment and our daily calls for action.'

Make a date in your diary for

Mon 31 October #FertilityFairness

We reveal what it's like to experience infertility and fertility treatment in the UK today. If patients can't access NHS-funded help, how much do they pay on average for private treatment? Do employers support their staff undergoing IVF? Do GPs provide the info patients need? How devastating is a diagnosis of infertility and is support available?

Tue 1 November #FertilityInTheWorkplace

Fertility treatment is still not recognised by the majority of employers as necessary medical treatment and there is still no legal right to time off work for fertility appointments. We are calling for employers to recognise fertility treatment as a clinical necessity and to provide appropriate medical leave.

Wednesday 2 November #HIMFertility

Male factor fertility problems are the most common reason for a couple to seek fertility treatment, yet far too often men's fertility is not tested in the first stages of a couple seeking medical help, leading to unnecessary delays and distress. We are calling for men's fertility to be tested in a timely manner at the same time as a woman's fertility is explored.

Thursday 3 November #FertilityEd

Fertility education is now part of the secondary school curriculum but what is taught is limited. We are calling for comprehensive fertility education for teenagers and young adults, so they understand fertility isn't a guarantee, how age and lifestyle impact fertility, and appreciate the limits of fertility treatments, including IVF and egg freezing.

Friday 4 November #TalkFertility

Infertility is so often a lonely experience - too many people struggle in silence. Yet talking about what you are facing and hearing how others have coped with their fertility journey can be extraordinarily helpful. We highlight patient experiences and signpost the support and info we provide, including our regional and specialty online groups.

https://fertilitynetworkuk.org/national-fertility-awareness-week-31-oct-4-november-2022/

Notes to editors:

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Media volunteers: the following people are potentially available.

Ruth Corden, 40, is childless not by choice. She and her husband Matthew tried for 10 years to have children, but it did not happen. They chose not to have fertility treatment. She still feels the pain of not being able to have children but says 'there can be life on the other side of the journey', and now describes herself as childfree. Ruth has 2 siblings, and she adores being an auntie to her nieces and nephews. She is available during National Fertility Awareness Week to speak about living childfree after ten years of trying.

#FertilityFairness

K, 33, from Nottinghamshire has unexplained infertility but was denied NHS-funded treatment because her husband has a child from a previous relationship. With no other options, the couple paid for private fertility treatment, taking out loans and leaving them in huge debt which they are still paying off. They were successful and have 2 IVF children. K donated eggs through egg sharing during her IVF. She says: 'I wanted to be able to give something back to other people going through such a hard time too... I am keen to get more fertility education into the classroom to raise awareness with our young generation.'

K, 40, and her husband, also 40, are from Dartford. K started trying to conceive 6 years ago but has ovulation problems; she was refused NHS medical help due to K's husband having a child from a previous marriage. They have since had 2 rounds of private treatment in the UK and 3 rounds in the Czech Republic. All have been unsuccessful.

A and her partner B are both 27 and live in Bedfordshire. They have male factor fertility problems and have been trying to conceive for 4 years but are only entitled to 1 NHS-funded IVF cycle because of where they live. Unfortunately, this was unsuccessful. A says: 'We have since been taking a break, spending time together and making a plan as move forward. The whole experience was far more emotionally and physically draining than we had ever imagined and we're scared about continuing again, but like many others, we have no choice. The financial pressure keeps us awake at night and it doesn't even guarantee success but how can you give up hope when it's all you've ever wanted? It seems so unfair that the NICE guidance recommends 3 rounds of IVF, yet so few integrated care boards offer this.'

S, 34 and her partner, 35, live in Glasgow and have access to 3 NHS-funded IVF cycles. They have male factor fertility problems. A second IVF cycle was successful in July 2022 and the couple still have two frozen embryos.

A and her husband, from Staffordshire, have been trying to conceive since 2019, when they were both 29. A has diminished ovarian reserve and ovulation problems. The couple have to date gone through 5 IVF cycles. Only one cycle was NHS-funded. She says: To fund IVF I sold my car, took out a loan and we have had pretty poor social lives for over 2 years now as all money goes on IVF. At the moment we are £30,000 out of pocket for IVF with no baby in our arms and a future which does not offer more reassurance that we will ever have a child with my eggs.' They are now looking at other routes to parenthood, including egg donation.

S, 39 and her partner moved to Portsmouth from London just before the pandemic, unaware they needed fertility treatment and not realising that the cut off age for NHS help in Hampshire is 35, rather than the recommended 42. GP problems in running tests delayed their treatment and then when finally referred back they were told S was too old. S challenged this but was told IVF was 'too high a risk for anyone over 35'. The couple couldn't afford private IVF in the UK so went to the Czech Republic for their first round of IVF this year which worked and S is now pregnant.

S says: 'If it worked first time, why are so many women being turned down this basic right of care purely based on their postcode? I could've had that treatment here and it still be successful but because the integrated care board says no, it's cost us our savings when someone who lives just 45 minutes from me can access different care.'

E, 37, and her partner, 36, live in Hertfordshire and were finally successful in May 2022 after 3 rounds of self-funded IVF costing around £24,000 in total. E wasn't able to access NHS-funding after being diagnosed with early menopause. She was told it was very unlikely IVF would be successful. E says of her third IVF cycle: 'It was our last chance, as we'd run out of funds and had our last 2 frozen embryos put back in, one of which took and produced us an absolutely beautiful baby boy!'

R, age 31, from Leeds, has been pregnant twice after fertility treatment but has lost both babies (experiencing a miscarriage and a termination for medical reasons). She has started treatment again but has had to self-fund as her area only offer 1 NHS funded IVF cycle. She

is a member of Fertility Network's Pregnancy loss support group. She says: 'It can feel very isolating going through fertility struggles and loss, and it has been really helpful to connect with other people who understand. I would encourage anyone going through something similar to reach out for support.

- L, 39, lives in East Sussex and is mum to a 2-year-old after IUI. She wasn't able to access NHS funding for fertility treatment as a single woman and a lesbian.
- S, 29, and her husband, B, 30, from Norfolk, have been trying to conceive for 5 years but have been denied NHS-funded IVF as S's BMI of 19 is below the eligibility criteria.

#FertilityInTheWorkplace

- N, 33, and her partner A, 35, live in Exeter and have been trying to conceive since the start of 2019. After two miscarriages, N was diagnosed with hyperthyroidism and low progesterone and A with male factor problems. Their only NHS-funded IVF cycles was unsuccessful and a second privately-funded cycle was too. Money is now an issue. N says: 'With the cost of living increase, we are struggling to work out how we will pay for our next cycle... we will likely have to take a loan out which is not what we wanted. We know physically, mentally, we can go again, but financially we don't know how we will.' N has started a fertility support group at her work and A is a member of HIMfertility.
- K, 37, and her husband, 35, live in Dorset and have been trying to conceive for over 5 years, with 5 failed embryo transfers. The majority of their treatment has been privately funded. K has recently taken a 6-month sabbatical from work because of the strains of fertility treatment. They plan to start treatment again in the New Year.
- J, 33, from Elgin, Moray experienced a lack of support from her employer during her 3 years of fertility treatment; all 7 embryo transfers were unsuccessful. Her firm did not have a fertility policy in place and dismissed her suggestion of having one. She eventually left her job because of the lack of support. Her new employers are supportive of her struggles and are supporting her as she begins her adoption journey.

#HIMfertility

- T, 31,and his partner, 31, live in Colchester. They need IVF to conceive as T's partner has one blocked fallopian tube and the other was removed after an ectopic pregnancy. The couple cannot access NHS-funded treatment because T's BMI is too high and he needs to lose weight to be eligible for help; his sperm parameters are fine. They were told to go away and come back in 6 months. The male BMI criteria are additional new criteria; they not part of national guidance. T and his partner also feel they received poor information from GPs which caused unnecessary delays and stress.
- A, 40, from Gravesend, Kent, has male factor fertility problems. After years of failed fertility treatment, he and his wife decided to stop treatment and pursue adoption. On his diagnosis of male infertility, A says: 'I felt worthless and less of a man and guilty as I couldn't give my wife the thing she wanted most in the world.' Counselling eventually helped him to come to terms with his situation. He says: 'The biggest mistake I made throughout the whole process was not seeking emotional support, being honest about how I felt and talking to those around me, especially my wife.'

J, 32, from Woolwich, London, has male factor fertility problems after surgery for undescended testicles as a child. He is waiting to have surgical sperm retrieval. He says: 'At the beginning of this whole process, I was scared to talk about my fertility issues to my family and friends, and I felt less of a man because I wasn't producing sperm. As a Black man with fertility issues, this has been the most challenging part of my life. Culturally, subjects like fertility are not addressed or discussed, they're pushed under the carpet.

L and his wife, both 36, live in Lincoln and tried to conceive for 3 years without success. They have unexplained infertility. They were due to start treatment in spring 2020 but their first cycle was cancelled days before egg collection as Covid lockdown happened. The finally began treatment later in 2020, a first embryo transfer was unsuccessful but a second was successful and their son was born in 2021. L says: 'As a man I often felt like I was on the outside looking in given the way referrals, consultations etc all focus on the woman. I also found the facilities to give samples for men incredibly demeaning (living in an area with no drop off hospital within an hour) which was a huge source of stress for me. I tried doing everything I could to improve myself to boost our chances but a lot of this was based on personal research. It ultimately became obsessive and my mental health really suffered as a result of the difficult struggle.'

#FertilityEd

L, 35 and her husband, D, 42, live in Windsor, where the cut off age for NHS-funded fertility treatment is 35, rather than the recommended 42. Covid delays and delays waiting for tests to be done put their NHS referral back as did suffering a miscarriage, which meant after trying to conceive for 4 years, they then had to try for another 2 years, before they were eligible for NHS treatment. By that time, L would have been over 35 and ineligible for NHS help in her area. The couple decided to pay for treatment; L had also been diagnosed with a low follicle count and her husband with male factor problems. The couple both gave up alcohol and caffeine and changed their diet to help improve sperm and egg quality. Their first IVF cycle was successful and their baby was born in summer 2022. L says: 'Prior to trying to conceive, I had no knowledge of various fertility complications and how lifestyle choices can impact your fertility. If I'd been aware of this and had had an opportunity to have fertility tests earlier in my 20s, then it would have had a big impact on my journey.'

C, 24, from Wales first visited her GP with concerns about her fertility when she was 19 but was told she was 'far too young to be considering starting a family anyway'. At 21 she was finally diagnosed with PCOS. She and her partner, 25, have begun NHS-funded treatment; they have had one failed transfer and are in the middle of a second one now.

#TalkFertility

F, 37, from Kettering, Northamptonshire, became a mother via surrogacy in Greece this year after fibroid surgery left her unable to carry a baby. She is a member of Fertility Network's Black women's fertility support group. F says: 'I felt frustrated with my body and experienced deep and profound grief for the loss of my inability to carry a child. I had difficulty finding any sources of support that I resonated with and were I felt represented as a black woman. Sadly, in black communities, reproductive health and fertility issues are not spoken about freely and continue to be stigmatised. Joining the Fertility Network's Black Women's Group was a tremendous source of comfort for me.'

- A, 40 and her husband, 42, live in Epsom, Surrey. They started trying for children 8 years ago and were referred for IVF in 2016. However, A was diagnosed with advanced ovarian cancer and after surgery went into surgical menopause. In 2021, they applied to adopt but were turned to due to A's health condition. A says: 'I want to share how I have worked through the grief of not being able to be a mum while dealing with a life-threatening cancer diagnosis.'
- L, 33, and her husband, 41, from Wrexham, got their miracle baby this year, after 5.5 years trying to conceive. L has severe endometriosis. Over the next three years, she had 8 surgeries, including endometriosis excision and bladder reconstruction. The pandemic then delayed their treatment for 18months but 1 round of IVF later, she became a mum in June this year and can't wait to celebrate this Christmas as a family of 3.
- R, 33, from Newcastle, was initially rebuffed by her GP when she spoke to them in 2018 about her concerns at being 30 and not having had a period for 4 years. After multiple GP visits and finally seeing a specific female GP, she was finally referred for further investigations. R then had to fight to be referred to a fertility clinic. At the clinic she was started on ovulation induction medication and she conceived naturally, and is about to become a mum. She says: 'It has felt like a hideously long journey and one which has certainly taken a toll on my mental health. If the first GP I saw had more knowledge and information on this, they may have been able to guide/council me through this process rather than sending me on my way with the pill and dismissing the importance of a 30-year-old woman having not had a period for 4 years.'
- R, age, and her husband are from South Ayrshire, Scotland. They have unexplained infertility and have been trying to conceive since 2019. NHS-funded IUI earlier this year was not successful. They are now on the NHS waiting list for IVF. R says: 'Waiting in between tests and treatment is the worst thing. I feel like I'm in limbo and often worry that I have been forgotten about!' R is a member of one of Fertility Network's regional support groups.
- P, 30 and her husband D, 38, live in Manchester. P has PCOS and endometriosis and her husband has azoospermia and they were successful on their 1st round of NHS-funded IVF in 2018. The couple are now trying to have a second child but are struggling with the cost of private IVF. P says: 'It is becoming ever so daunting to us that we may never be able to afford it. We are currently in debt and have had to take out a loan, we have looked into selling the house but financially we would not be any better off with legal fees etc. We have reached out to family and friends but nobody we know is in a position to help. I have even donated my eggs to raise funds for another round.'
- S, 34, and her husband, 34, live in Leeds. Her husband has had surgery and treatment for testicular cancer, and S has surgery for a uterine fibroid and treatment for endometrial hyperplasia (which meant a year of progesterone treatment and waiting for a negative biopsy before being able to start fertility treatment). NHS-funded ICSI, followed by two embryo transfers has so far been unsuccessful. S says: 'We're at the point of deciding whether we can emotionally endure another transfer or whether we move onto the adoption process. The hardest part about this entire journey is definitely the waiting and feeling as though time is simultaneously slipping away yet going too slowly.'

- F, 41, from Milton Keynes, is childless-not-by-choice. She has PCOS and endometriosis and has been trying to conceive for over 7 years. She has had failed IVF cycles and experienced miscarriages after IVF and a natural pregnancy. She is now focusing on a childless life.
- J, 33, from Elgin, Moray turned to friends for support through her 3 years of unsuccessful fertility treatment. She says: 'I have two amazing friends who did everything they possibly could to support us. One friend came to appointments with me, checked on me and came to support with every negative test. My second friend made an "ivf survival kit" with a water bottle to keep me hydrated, snacks, colourful plasters for my injections and books on mindfulness. She also included homemade vouchers for practical support, like doing our shopping or a shoulder to cry on. Fertility treatment is so difficult and there is so little support available where I live. I don't know how I would have made it through without them.'
- K, 36, lives in Glasgow, has unexplained infertility and was trying to conceive for 3.5 years until her marriage ended. Following Covid delays, she had one unsuccessful NHS-funded IVF cycle with her then husband but is now single. Their fertility struggles were a factor in their relationship breakdown.
- A, 31, and her partner, 33, live in Sussex and have been trying to conceive since 2019. A has PCOS and has a BMI of 32 and is unable to start NHS-funded treatment until her BMI is 30. A says: 'I was told to come back once I weighed less, and I am not the first person this has happened to. It is tough to be treated like this when you are already struggling with the grief of being unable to have a baby.'
- A, 35 and her partner M, 42, live in Stirling, Scotland, have unexplained infertility and have been trying to conceive for nearly 5 years. They have been able to access 3 full NHS-funded IVF cycles, however, none have been successful. A very recent self-funded cycle was also unsuccessful. A says: 'We are heart broken and struggling with what we should do next.' A is a member of Fertility Network's online support groups.
- A, 38, from Wales experienced an ectopic pregnancy in 2011 and lost a Fallopian tube. She also has two uteruses. She and her husband accessed NHS-funded fertility treatment, 2 fresh cycles and 1 frozen cycle but were not successful. They also paid for 4 unsuccessful private embryo transfers. Her last transfer was in 2018 and she has 2 embryos remaining. They have decided to move on from treatment. She says: 'At the point of the last transfer I was broken. All I wanted was to be a mother. But I needed to stop, just for a bit. Before we knew it a year had passed. And I felt relieved. The freedom of the pressure, the pain and the constant worry was liberating. Now, honestly, I am happy. We wish it had worked out differently, but it didn't and that's ok.'
- R, 32 and her partner L, 33 live in Warrington, Cheshire and have access to 3 NHS-funded IVF cycles. They have male factor and ovulation problems. After the first unsuccessful round if ICSI, R developed OHSS. They are undergoing a second ICSI round. Posting on Instagram has helped R. She says: 'I have connected with so many amazing people... it's kind of given me the boost I need.'
- N, 29, from Coventry, has endometriosis and diminished ovarian reserve. A chance blood test informed her about her low ovarian reserve. She has tried 2 rounds of egg freezing: the first in Greece with a poor response and the second was cancelled because of a poor response.

- C, 26, lives in Leicester with her partner, 22. She has experienced ovulation problems since she was 16, has PCOS and has had 2 miscarriages in the last 3 years. After a very disappointing experience with her former GP (including waiting nearly 3 years for a referral to gynaecology), she recently changed GPs, has been diagnosed with unexplained infertility and is now on a gynaecology waiting list.
- D, 34, from Surrey has secondary infertility. Since having her daughter 4 years ago, she has had an ectopic pregnancy and a miscarriage. She says: 'No one can ever prepare you for how secondary infertility makes you feel. I love my daughter more than anything but when on a regular basis she is saying to you "Mummy I want to be a big sister", it breaks your heart knowing you may never be able to give that to her.'
- S, 32, from Middlesborough, has secondary infertility. She and her husband, 34, have a 7 year-old son and have been trying to conceive for the last 5 years.
- E, 38, is hoping to become a solo mum by choice. Her decision was triggered by discovering in 2020, when she hoped to freeze her eggs, that her ovarian reserve was low. She was advised either to try solo now or risk not having children. So far she has had 2 IVF cycles but has not yet been successful. She has frozen embryos and is still trying. She says: 'The experience has been mentally and physically hard. My friends have been my lifeline and support throughout my journey and although I remain hopeful, it still heart-breaking to receive the disappointment after the two week wait.'

A and his wife are both 35, of Indian origin. A has azoospermia and his wife also has genetic fertility issues. They feel their fertility was not tested in a timely manner and say, there were 'lots of issues around timeframes and even getting basic tests done via the GP for my wife; they chose to pay for fertility treatment. Their first IVF baby was born in 2019 and their second one in July this year.

E, 26, is from Hampshire and has been trying to conceive for 5 years with her partner. She went to her GP after two years of trying but was turned away and advised her situation was not considered a problem until she was 25. She returned to her GP in 2019 with pelvic pain and was finally referred for treatment. She was diagnosed with ovarian cysts, low ovarian reserve and blocked fallopian tubes, the latter probably a result of surgery to remove her appendix as a child. Covid then delayed their journey further. Four IVF rounds have so far been unsuccessful and they are waiting to transfer their remaining frozen embryo.

L and her partner are both 45 and live in north Wales. L experienced secondary infertility after the birth of her first baby in 2010, having 4 miscarriages. She self-diagnosed she had an iodine deficiency due to an underactive thyroid (after watching a farming programme on TV), treated herself with special iodine salt, demanded her GP refer her to a thyroid specialist and went on to conceive and carry a second baby. She says: 'It was a real struggle to get them to listen... but there was a rainbow at the end of a very dark tunnel.'

F, 40, from Aberdeen is a solo mum by choice. She always thought she would meet someone, get married and have children, but at 36, she decided to try to conceive as a single woman. She began self-funded IUI in 2019, but prior to treatment had to lose 2 stone. 2 IUI rounds were unsuccessful. She then began IVF in 2020. She was successful on her 2nd attempt. Her baby girl was born this spring.

- J, 37, from Leicestershire, is hoping to be a single mum by choice using donor sperm via IVF. A first embryo transfer earlier this year was unsuccessful; she has recently had a second embryo transfer and is at the beginning of her second trimester. She says: 'I decided to take this path after not having met anyone I saw a long-term future with, and REALLY wanting to be a mum. I wasn't willing to settle for just anyone to have a child. I used to joke through my 20's that if I was single at 36, I would do it on my own.'
- H, 39, is now a solo mum by choice from Port Talbot, South Wales. H had tried to conceive for 5 years with her partner and was about to start privately-funded IVF when they separated. She then sought NHS-funded treatment using her own eggs and donor sperm. At first her funding request was declined as she was told her low ovarian reserve suggested she had a less than 10% chance of conceiving with her own eggs. She appealed the decision and was told the NHS would fund one round using her own eggs and donor sperm, and a second round with donor eggs. she did have a poor response to stimulation in terms of number of eggs collected, but the eggs were of good quality and she was successful on the 1st IVF attempt and is now a solo mum.
- R, 39, from Faringdon, Oxfordshire, started trying to conceive in 2019. Tests showed low ovarian reserve. As she was about to start IVF, clinics closed due to Covid. 3 IVF cycles were unsuccessful. She then tried a cycle of natural modified IVF but ovulated before any eggs could be collected. She says: 'We were devastated but discovered 2 weeks later we had conceived naturally from that same escapee egg. Our miracle daughter is now 1 and worth every second of heartache along the way.' Sadly, though, R's periods never came back after having her daughter and she has now been diagnosed with premature ovarian failure. She says: 'Our hopes of a (biological) second child are now over and we are still coming to terms with this new blow.'
- R, 34 and her husband S, 37, live in Ruislip and are of Indian background. They have male factor fertility problems. They were able to access 2 NHS-funded IVF cycles and were successful at the second attempt and now have a 14-month old baby. R says: 'I was very open with family and friends, they were a great source of support. IVF challenged our relationship, but we spoke a lot and got on to the same page before our second round of IVF, which I think helped a lot. We were fortunate and are really happy to share our story and help others in any way we can especially as I find the Asian community is still reserved about fertility troubles.'
- P, 30, from Newport, South Wales has endometriosis, which took nearly 8 years to be diagnosed. P and her husband, 42, have been trying to conceive for 9 years. They are just starting their first round of NHS-funded IVF.
- E, 36, from Cardiff, has PCOS and feels she wasn't listened to properly or investigated adequately by her GP about her concerns about her fertility or weight management. When she was eventually referred for further tests in secondary care, lengthy delays meant she felt pushed to pay privately for these tests, in order to feel like she was making progress and to alleviate some anxiety and stress. She has unexplained infertility and is trying to conceive with Clomid.
- H, 33 and her husband, 36, live in Oxford. They have been trying to conceive for over 4 years. They have male factor fertility problems and low ovarian reserve. H had to lose

around 50lbs to access NHS help but after that the NHS wait list was so long, they couple paid privately for an IVF round. That was unsuccessful, as was a later NHS-funded round and a second privately-funded cycle. They are now considering a last cycle.

ENDS

- National Fertility Awareness Week 31 Oct-4 Nov seeks to change perceptions, provide support and raise funds for everyone struggling with fertility issues.
- Fertility Network UK provides practical and emotional support, information and advice
 for anyone experiencing fertility issues. The charity works to raise the profile and
 understanding of fertility issues and to push for timely and equitable provision of
 fertility treatment throughout the UK. www.fertilitynetworkuk.org
- Fertility Network UK provides a free <u>Support Line</u> and regional and specialty online <u>fertility support groups.</u>
- Fertility Network UK supports people. We rely on voluntary donations to continue our vital work. You can donate now by visiting https://fertilitynetworkuk.org/donate/