

Under embargo until: 00.01 am 31 October 2022

The far-reaching trauma of infertility: Fertility Network UK survey reveals the emotional, financial and career impact of infertility and fertility treatment

National Fertility Awareness Week 31 October - 4 November 2022 #Fighting4Fertility

Fertility Network UK's survey of approaching 1,300 fertility patients in the UK reveals the devastating toll infertility wreaks on people's mental health, relationships, finances and career. Released at the start of National Fertility Awareness Week 2022, the findings also highlight the lack of information provided by GPs and the limited support options.

Gwenda Burns, chief executive of Fertility Network UK said: 'Fertility Network UK's major new survey reveals the far-reaching trauma of infertility, painting a stark, distressing picture of what it is like to experience infertility and fertility treatment in the UK.'

'Fertility patients encounter a perfect storm: not being able to have the child you long for is emotionally devastating, but then many fertility patients face a series of other hurdles, including potentially paying financially crippling amounts of money for their necessary medical treatment, having their career damaged, not getting information from their GP, experiencing their relationships deteriorate, and being unable to access the mental support they need.'

'This is unacceptable. Infertility is a disease and is as deserving of medical help and support as any other clinical condition. Yet our findings, launched at the start of National Fertility Awareness Week 2022, shows how much more needs to be done. That's why this week we are #Fighting4Fertility.'

Fertility Network UK's survey was conducted with Dr Nicky Payne, Middlesex University London and found:

Mental health

- 4 out of 10 respondents experienced suicidal feelings: 30% reported suicidal feelings sometimes or occasionally, while 10% experienced suicidal feelings often or all the time
- Approaching half (47%) of respondents experienced feelings of depression often or all the time, while the vast majority (83%) felt sad, frustrated and worried often or all the time.

Finances

- Two-thirds of patients (63%) had to pay for their own medical treatment.
- The average cost of investigations and treatment was £13,750.
- Around 1 in 10 couples (12%) spent more than £30,000 and a few (0.5%) spent over £100,000.

Career

- More than 1 in 10 respondents (15%) either reduced their hours or left their job.
- Over a third (36%) of respondents felt their career was damaged as a result of fertility treatment, and the majority (58%) felt concerned that fertility treatment would affect their career prospects.
- Only a quarter (25%) reported the existence of a supportive workplace policy, while 1 in 5 (19%) weren't sure if a workplace fertility policy existed.
- Less than half (45%) of respondents felt they received really good support from their employer.
- The majority of respondents (77%) did disclose they were undergoing fertility treatment to their employer, but of these less than half (47%) said reasonable adjustments were made for them.

Relationships

• The majority of respondents (59%) reported some detrimental impact of fertility problems and/or treatment on their relationship with their partner, while 2% of respondents reported their relationship had ended as a result.

Information & Support

- Approaching half (44%) of respondents sought help from Fertility Network UK, the nation's leading fertility charity.
- Three-quarters of respondents (75%) felt their GP did not provide sufficient information about fertility problems and treatment and 7% were not sure. Less than one-fifth (18%) were satisfied with the information GPs provided.

- The majority of respondents (78%) would have liked to have counselling if it was free.
 Half of respondents (51%) did have counselling, but most of these (59%) had to fund some of it themselves.
- Just over a quarter of respondents (27%) attended a fertility support group but nearly half (47%) who didn't attend would have liked to if one was nearby.

Commenting on the survey, Dr Raj Mathur, chair of the British Fertility Society, said: "This survey gives a sobering - some might say, shocking - insight into the wellbeing of subfertile people, especially women, in Britain today. For 47% to report feelings of depression and as many as 10% to report suicidal thoughts often or all of the time is unacceptable."

'This survey uncovers effects far beyond the physical health of patients. We must do better as a society and a health system in looking after patients with fertility problems. Above all, this must begin with a fair funding settlement for fertility treatment across the UK, based on full implementation of the evidence-based recommendations made by NICE. We must improve awareness of fertility matters and the effect of subfertility on patients, among healthcare commissioners, professionals and wider society.'

Commenting further on the survey, Fertility Network's chief executive Gwenda Burns added: 'The survey findings released today by Fertility Network UK also build on our previous infertility impact survey with Middlesex University in 2016. A comparison of the two reveals fertility patients are still being failed on many counts.'

'More patients now have to pay for their fertility treatment and continue to pay eye-watering amounts of money; the number of respondents reporting a supportive workplace policy has stayed the same at just one-quarter (25%), and three-quarters of patients still feel let down by their GP when it comes to providing appropriate information.'

Respondents to the survey, which was conducted between April - July 2022, were mainly white (93%) women (98%) in a heterosexual relationship (90%). The average current age of respondents was 36.6 years and the average age when they started treatment was 33.7 years. They had on average been trying to conceive for 4.1 years. The majority (69%) were living in England, 18% in Scotland, 7% in Wales and 6% in Northern Ireland.

A copy of the full report The Impact of Fertility Challenges and Treatment can be viewed here.

We have a Fertility Network team in each country in the UK.

Notes to editors:

Contact: Catherine Hill, communications manager on 07469-660845 media@fertilitynetworkuk.org We have a Fertility Network team in each country in the UK.

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.

Financial impact

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!'

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.'

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.

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.

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.'

Relationship impact

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.'

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.

Mental health impact

- 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.'
- 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.'

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.'

R 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.

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.'

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.'

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.

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.

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.'

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.'

- 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.'
- 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.'

Lack of information

- 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.
- 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.'
- 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.
- 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.

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.

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.'

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.

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.'

Impact in the workplace

- 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.

Having to pay for private treatment as NHS help not available or rationed

- 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.
- 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.
- 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.
- 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 of 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.'

Success stories

- 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.
- 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.

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/