THE DAISY NETWORK UPDATE

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NEW YEAR'S RESOLUTIONS FOR DAISY

Welcome to the spring edition of Update and a belated happy 2015! As you know, there have been several changes to the committee recently and we have been working hard exploring ways we can improve the service that Daisy provides. Over the coming months we will be improving the website and social media presence, developing local support networks and focusing on raising awareness, particularly amongst the GP community. We really appreciated the feedback from the recent member survey and will be using this to help guide us as we develop the Daisy Network.

We hope many of you will be able to join us on Saturday 6 June at Chelsea & Westminster Hospital, London, for the Daisy Network annual conference. We have some fantastic speakers lined up and it should be a great day.

Marie and Kate

ANNUAL CONFERENCE DATE ANNOUNCED!
Turn to page 5 for details.

IN THIS ISSUE

ASK THE EXPERTS

Question:
I've heard I should have a bone density scan. How often should I have one and what can I do to help maintain good bone density?

Dr Kate Maclaran answers:
Bone health is a major concern in POI. Bone tissue is continuously in a state of turnover, with old bone being resorbed – i.e. broken down and dispersed – and new bone being made. When there is a lack of oestrogen (as in POI), more bone is resorbed than is made, leading to bone loss.

Taking oestrogen replacement, in the form of HRT or the combined oral contraceptive pill, can help prevent bone loss and sometimes increases bone density. Bone density is assessed using a DXA bone scan of the lower spine and hip. It is a good idea to have a DXA when you are first diagnosed with POI as a baseline measurement. The result of a DXA will be either normal, osteopenia (meaning thin bones) or osteoporosis. Women with osteoporosis are more likely to experience fractures (broken bones). The frequency of bone scans will depend on the initial values and whether you are taking oestrogen replacement or not but they are usually repeated after around 3–5 years.

There are several other things you can do to keep your bones healthy. Ensure you are eating a healthy, varied, well-balanced diet incorporating foods which are rich in calcium and vitamin D. Aim for around 1,000 mg calcium daily and 800 IU of vitamin D.

Calcium is found in dairy foods, oily fish, green leafy vegetables, bread, cereals and pulses. Most of our vitamin D comes from sunlight exposure but it is also in dairy, oily fish and eggs. Minimising caffeine and alcohol and avoiding smoking will be beneficial for bone health. Also it is very important to take regular weight-bearing exercise.

More information on bone health can be found in our leaflet on osteoporosis and also on the National Osteoporosis Society website, www.nos.org.uk.

Question:
What are my HRT options? I was diagnosed with POI at 16 and have been on HRT and the Pill. I'm currently on nothing as I suffered from deep vein thrombosis five years ago and was told to stop taking the Pill. I seem to have slipped through the net with regard to my GP putting me on suitable treatment since then. In that time, I've had one unsuccessful cycle of egg donation and haven't been on any form of HRT since. What are my best options? I'm now 34 and overweight but know I need to be on something.

Dr John Stevenson answers:
Most deep vein thromboses (DVT) occur after a period of immobilisation, such as following surgery or long-distance travel. The oral contraceptive (OC) pill itself does increase the risk of DVT. This risk is highest when you first start on the OC, with the risk decreasing steadily over the first 12 months or so. Rarely, a DVT may occur because of a blood clotting abnormality (thrombophilia) which may be inherited. You may have been tested for this. Hormone replacement therapy (HRT) has a much lower risk of DVT because the oestrogen used is much less potent than that in the OC.

It is also dependent on the dose of oestrogen, with higher doses carrying greater risk, and on the route of administration, with oral HRT carrying a greater risk than gels or patches. It would therefore be safest for you to go onto HRT with either skin patches or gel.

This route of administration has not been shown to increase the risk of blood clots, even in those who are at increased risk because of their weight or an inherited risk. If you use patches, they can also provide progestogen through the patch, necessary to prevent the lining of the womb overgrowing. If you use an oestrogen gel, you would need to take progesterone/progestogen tablets additionally. These do not affect the risk of blood clots.

Question:
How can I avoid putting on weight around my middle during and after the menopause?

Marilyn Glenville answers:
Unfortunately your body is trying to compensate for the drop in hormones caused by the menopause. Fat cells, especially around the middle of the body, are a manufacturing plant for oestrogen so weight around the middle can naturally increase as your body tries to compensate for lower oestrogen levels in order to protect your bone health.

It is important to think about eating a low-GI diet and avoiding, where possible, added sugar and refined complex carbohydrates such as white flour and white pasta as these will cause higher levels of insulin release, which will cause more weight gain. Make sure that you are eating little and often to keep your blood glucose (sugar) stable.

Protein slows down the rate at which the stomach processes food and slows the passage of the carbohydrates with it. As soon as you add a protein (be it animal or vegetable) to a carbohydrate you change it into a slower-releasing carbohydrate and less insulin is produced to deal with it. Eat essential fats, particularly omega 3 essential fatty acids, like oily fish and flaxseeds as they help to boost your metabolism.

Watch your stress levels as the release of the stress hormone cortisol will cause more weight to go around the middle. I use a supplement called Tranquil Woman Support in the clinic to help women with their busy lifestyles (www.naturalhealthpractice.com).

As we get older we naturally lose muscle which makes it harder to burn fat. Exercise is important because the more muscle you have the more fat you burn. Try to include more weight resistance exercise as this helps to build muscle which is metabolically active.

GOT A QUESTION?

Our experts are here to help you. If you'd like their advice on any issue, big or small, email your question to editor@daisynetwork.org.uk or write to us at:

The Daisy Network, PO Box 183, Rossendale, BB4 6WZ

We will protect your anonymity at all times.

Chrissie Hosking is an experienced, accredited integrative counsellor and psychotherapist (MA, CTA). She has a special interest in the psychological impact of premature ovarian insufficiency and infertility. She runs her own independent therapy practice in the Midlands. Chrissie is also available to talk to if you take advantage of the Daisy Network tele-counselling.

Nick Panay (BSc, MBBS, MRCOG, MFFP) has worked in obstetrics and gynaecology for more than ten years. As director of the West London Menopause & PMS Centre at Queen Charlotte's & Chelsea and Chelsea & Westminster Hospitals, he heads a busy clinical and research team that publishes widely. He also presents at scientific meetings, trains health professionals at all levels and is an honorary senior lecturer at Imperial College London.

Dr Gerard Conway is clinical lead in endocrinology at University College London Hospital. Dr Conway's research into ovarian function has formed the basis of more than 120 academic publications. His research focuses on the causes of ovarian insufficiency and his clinical research projects include studying the cardiovascular effects of oestrogen in young women. Dr Conway has been involved with the Daisy Network since its inaugural meeting in 1995.

Dani Singer is a psychotherapist and counsellor (UKCP Reg./ MBACP Senior Accr.). She specialises in women's health, particularly in the area of premature ovarian insufficiency, and is actively involved in research on this topic. She often gives talks on the psychological impact of POI to health professionals.

Dr Marilyn Glenville (PhD) is the UK's leading nutritionist specialising in women's health. She is the former President of the Food and Health Forum at the Royal Society of Medicine and the author of a number of internationally best-selling books including *The Natural Health Bible for Women* and *Natural Solutions to the Menopause*. For more information go to www.marilynglenville.com.

Nigel Denby is the UK's proclaimed GDA (Guideline Daily Amount) Diet Doctor. He now runs his own private practice in Harley Street specialising in weight management, PMS/POI, menopause, irritable bowel syndrome and food intolerance.

SAVE THE DATE

DAISY NETWORK ANNUAL CONFERENCE SATURDAY 6 JUNE 2015

The date for the next annual conference has now been confirmed, so put it in your diary! The conference will be held at Chelsea & Westminster Hospital, 369 Fulham Road, London, SW10 9NH. Because our new co-chairs have links with the hospital, we have been able to reduce our venue hire expenses. As a result, tickets for the event will be cheaper this year.

Tickets will cost £25 for members and £30 for non-members, including lunch and break-time refreshments. You are very welcome to bring a partner or other supporter, but we regret that children under the age of 12 are not allowed out of sensitivity to our members.

Work to organise the conference is still under way, but Dr Heather Currie and Joan Pitkin have currently agreed to speak.

Heather Currie is an associate specialist gynaecologist and obstetrician at Dumfries and Galloway Royal Infirmary, Dumfries. She is Honorary Secretary of the British Menopause Society and a member of several other medical groups and advisory panels. A specialist in the

menopause, premenstrual syndrome and sub-fertility, she founded the magazine *Menopause Matters* and has written and published widely on women's health.

Joan Pitkin is a consultant gynaecologist at Northwick Park and St Mark's Hospitals, North-West London Hospitals NHS Trust, and Honorary Clinical Senior Lecturer at the Faculty of Medicine, Imperial College. She also provides advice and treatment for urogynaecological problems in the private sector. Joan supervises research projects and is involved in lecturing as well. She also sits on various councils and committees.

As well as talks by leading specialists, you can expect break-out sessions and a chance to meet and mingle with other Daisy members throughout the day. Further details will follow in due course. We'll let you know when tickets go on sale.

STUFFED APPLE CRUMBLE

A POI-friendly recipe by Anna, a Daisy member and nutritionist

We all know that calcium is essential for bone health, and hopefully, we all know where to find it. Dessert isn't usually the first place you would look, but these indulgent little apples contain 25% of the daily recommended intake (when served with Greek yogurt). That's because they contain the most calcium-packed nut of them all: almonds. As if that isn't enough, they are free from dessert culprits like sugar, flour and butter.

Ingredients

6 Braeburn apples
A large bowl of water with the juice of half a lemon

For the filling:

75 g dried dates, roughly chopped
100 ml milk (or dairy-free alternative)
2 tbsp maple syrup
½ tsp cinnamon
2 heaped tbsp almond butter

For the topping:

100 g almonds
1 tbsp rolled oats
1 tbsp coconut oil
2 tbsp maple syrup
Full-fat Greek yogurt to serve

Method

Turn your oven to 180 °C. While it's still preheating, pop the apples in for about 5 minutes until they warm up. This will make it easier for you to hollow them out.

Fill a large bowl with water and lemon juice and have it ready to put the apples in, to stop them from browning. Slice off the top of the apples and use a melon baller or a teaspoon to scoop out the centre of the apples, being careful not to pierce the skin. Throw away the seeds but keep the rest of the pulp and put it in the bowl of water.

Place the dates, milk, maple syrup and cinnamon into a blender and blitz for about 30 seconds, then add the almond butter and blitz for a further 30 seconds.

Drain the apple pulp you scooped out earlier and dab with some kitchen towel to get rid of any excess liquid. Then stir in the almond butter mixture and give it a good mix so everything is well combined.

Place the hollowed-out apples in a muffin tray to stop them from tipping over and fill them up with the apple mixture.

To make the crumble, place the almonds and rolled oats into a blender and blitz them until the almonds are chopped up but not completely powdered.

Then mix in the maple syrup and coconut oil. You may need to place the coconut oil in the microwave for a few seconds, as it's solid at room temperature.

Then spoon about a tablespoon of the crumble on top of each apple. Bake for 25 minutes.

Sprinkle some extra cinnamon on top and serve with a large scoop of Greek yogurt.

Follow Anna on Twitter (https://twitter.com/AnnaVrakas) to be one of the first to find out when she comes up with new recipes.

WE NEED YOU!

THE DAISY NETWORK

We are looking for a couple of new member representatives to help run Daisy. We are particularly keen to find someone to coordinate local groups and a second volunteer to manage our online forum and social media as we are aware that there is room for improvement in these areas. If you think you could help us in either of these ways or have other skills which you would like to put to good use, please email daisy@daisynetwork.org.uk. Daisy is a patient-run organisation which relies entirely on volunteers and has no paid members of staff, so it's crucial that members come forward to help continue its valuable work.

SURVEY

We are always keen to hear what you think and make sure we are doing all we can to ensure Daisy gives you the support you want and need. To gain as much member feedback as possible, we asked you to complete an online survey a few weeks ago. The survey was still open at the time of going to press, so an analysis of the results will be included in the next newsletter. Thank you to everyone who took the time to complete it!

COMMITTEE AND CONSTITUTIONAL CHANGES

As we reported in the December issue, almost all of the key positions at Daisy changed hands last October. For the time being, Marie and Kate have been co-opted as co-chairs until the AGM, which will be held during our annual conference in June. You will then be asked to vote to confirm both of them and elect the other new committee members, who would then become trustees. The prospective new committee members are Patricia (vice-chair), Jocelyn (secretary), Vicki (*Update* editor) and current patron Dani. Along with the two new co-chairs, they are hoping to join existing trustees Erica (membership and PO Box manager) and John (treasurer). Currently, all committee members – both new and old – have to be elected at the AGM each year. We will be running profiles of the existing and prospective committee members in the next issue of *Update*.

As a registered charity, Daisy has to abide by a constitution, which the new team feel needs updating. We will discuss what changes we consider are necessary at our next meeting and present these at the AGM for you to vote on as well.

UNDERSTANDING TEST RESULTS FOR PREMATURE OVARIAN INSUFFICIENCY

The prospect of understanding blood results can be very complicated at the best of times. This can be even more daunting when you are confused about why your periods have stopped or have become irregular, especially when your doctor thinks you may have gone through the menopause. Understanding the cyclical nature of periods can be a specialist field. With this article, I hope to simplify the interpretation of some blood tests that may be performed by either your GP or a gynaecologist. As a result, I hope to make the journey of understanding your diagnosis of POI a little easier. By Dr Brianna Cloke.

1. Pregnancy test

This may seem a counter-intuitive test but it is standard practice to perform this if a woman has missed her period for a few months. Don't be offended because pregnancy is much more common in young women than premature ovarian insufficiency.

2. FSH

FSH stands for follicle-stimulating hormone. This hormone is produced by the pituitary gland in the brain. It has the important role of telling the ovary to start producing eggs and its level changes throughout a woman's natural monthly cycle. However, when the ovaries stop producing eggs (which is what happens with POI), the brain can sense the lack of eggs because the oestrogen levels (see point 3) are low. The brain then tries to compensate by producing even more FSH, in essence to try to get the ovaries to work. This is known as negative feedback and is the reason why levels of this hormone are elevated in POI. There are, however, two important points about this test. Firstly, if you are having scanty or irregular periods, then it is best that this blood test is performed between day 2 and day 4 of bleeding. It is inaccurate to do this blood test later in the cycle as FSH levels increase normally in a natural cycle. If your periods have stopped altogether, then this test can be performed at any time. The second important point is that one result is not sufficient to make a diagnosis of POI. A diagnosis can only be established after two blood tests showing elevated FSH on two occasions at least six weeks apart. It is obviously distressing to wait for such a long time but it is critical to get the diagnosis correct.

3. Oestrogens

These are the female sex hormones that are produced from the cells surrounding the eggs within the ovaries. Oestrogens are also the hormones present in the combined contraceptive pill and HRT. The most commonly tested type of oestrogen in the blood is oestradiol. If the ovaries are not producing eggs any more then the oestradiol levels will be low on blood tests, and this is what triggers the brain to produce more FSH. In POI, low oestrogen levels should be treated with HRT to prevent the bones thinning.

4. Prolactin

This is another hormone also produced by the pituitary gland in the brain. If you tell your doctor that your periods have stopped, he or she may test this hormone because high prolactin levels can cause periods to stop. However, prolactin levels are not altered in POI and your doctor may have just done the test in the first instance to work out why your periods have stopped.

The remaining tests are specialist ones and are more likely to be performed by a hospital gynaecologist.

5. Antibody test

There are many causes of POI and it can occasionally be associated with an autoimmune disease (although the cause usually remains unknown or 'idiopathic'). An autoimmune disease occurs when a person's own immune system attacks a part of his or her own body. Your doctor may test for anti-thyroid or anti-adrenal antibodies. If these are positive, then your doctor will explain this in more detail.

6. AMH

AMH stands for anti-Müllerian hormone. This is a relatively new test. At the moment it is used to check a woman's ovarian reserve but currently, it can only be interpreted if a woman does not have POI. Furthermore, and unfortunately, it cannot be used to predict POI. About 5% of women with POI can fall pregnant spontaneously, but again, AMH cannot be utilised to assess the chances of this.

7. Karyotype and FMR1 gene test

The human body is made up of billions of individual cells. Most of these cells contain 23 pairs of chromosomes. The chromosomes contain the 21,000 genes which instruct the body how to develop and work properly. Genetic conditions can occur either because of a problem with the chromosomes or with the individual genes.

A karyotype test counts the number of chromosomes and also checks if any of the chromosomes are mixed up. The most common diagnosis that can be picked up on a karyotype test in POI is Turner syndrome. A genetic test can look for abnormalities in the FMR1 gene, which is associated with POI. At the moment these are the only two well-characterised genetic conditions which doctors can test for but together they only account for the cause in 2–5% of POI cases. If you test positive for either of these, your doctor should refer you to a genetic counsellor.

IN THE NEWS

INNOVATIVE BONE PASTE COULD REVERSE OSTEOPOROSIS

Researchers at the University of Nottingham are developing a bone paste which could repair the damage caused by osteoporosis. Made from stem cells enclosed in tiny spheres of calcium phosphate, the non-invasive paste would be injected into areas where a patient's bones have become brittle. Stem cells can regenerate bone, but do not usually survive transplantation. Calcium phosphate is the main mineral in bones and could provide a protective capsule for the cells.

Britain currently has some three million osteoporosis sufferers. Although many are elderly, the condition can also be caused by various other factors including genes, insufficient exercise and a poor diet. Brittle bones are also a major concern for women diagnosed with premature ovarian insufficiency (POI), as falling oestrogen levels cause bone loss. According to the National Osteoporosis Society, fractures associated with osteoporosis cost the NHS approximately £1.7 billion in health and social care each year. It is hoped that the bone paste would proactively reduce fractures, giving patients better quality of life and saving the health service money.

One of the researchers, Dr Ifty Ahmed, said his team wanted to develop a preventative treatment: "Our aim would be to use screening to spot people who are at risk, then strengthen their bones before they get fractures. It means that rather than waiting until people have a fall and break something, we would try to stop that ever happening, along with the consequences, loss of independence, surgery and secondary illnesses."

Although the bone paste sounds promising, it will draw criticism from pro-life campaigners as stem cells are often harvested from human embryos. Nevertheless, it offers a glimmer of hope. The paste has not yet been tested on humans but Dr Ahmed believes that, if successful, the treatment could be administered in a single day.

GENETIC MUTATION LINKED TO POI

A new study by researchers at Tel Aviv University has revealed a previously unidentified cause of premature ovarian insufficiency (POI). The scientists found a unique mutation in a gene known as SYCE1 which had never before been linked to POI in humans. Although existing research had shown that the genes involved in chromosome duplication and division could cause ovarian failure in animals, this is the first time a mutation of this kind has been detected in humans.

The research was led by Dr Liat de Vries and Prof. Lina Basel-Vanagaite. Although POI has been linked with a number of conditions in the past – such as Turner syndrome – the cause is unknown in 90% of cases. Around 1% of women worldwide are thought to experience POI. The study was inspired by two young women from the same family who went to Dr de Vries for treatment. Each had a different set of typical POI symptoms. Having eliminated other possible causes such as autoimmune diseases, the research team worked to track down the genetic cause of the condition in the two girls.

Dr de Vries said: "One of my main topics of interest is puberty. The clinical presentation of the two sisters ... was interesting. One had reached puberty and was almost fully developed but didn't have menses [periods]. The second, 16 years old, showed no signs of development whatsoever."

The scientists completed genotyping on the patients, their parents and their siblings. Genotyping is a method of identifying differences in individuals' genetic make-up by looking at their DNA sequence. By doing this, the researchers identified a mutation affecting the SYCE1 gene in both of the girls with POI. Several members of the family were found to carry the mutation, but one unaffected sister did not.

"By identifying the genetic mutation, we saved the family a lot of heartache by presenting evidence that any chance of inducing fertility in these two girls is slight," commented Dr de Vries. "As bad as the news is, at least they will not spend years on fertility treatments and will instead invest efforts in acquiring an egg donation, for example. Knowledge is half the battle – and now the entire family knows it should undergo genetic testing for this mutation."

WOMAN HAS BABY 15 YEARS AFTER POI DIAGNOSIS

After being diagnosed with POI (premature ovarian insufficiency) in her 20s, Allison Noyce was told she would never conceive naturally. So when she started experiencing stomach pains and felt a lump in her tummy 15 years later, she and her husband were terrified that something was seriously wrong. Her doctor thought the lump was "probably a large cyst" and sent Allison to hospital for tests.

However, an ultrasound showed that – against all the odds – Allison was in fact heavily pregnant. She said: "We were overcome with emotion when the woman doing an ultrasound said I was eight months pregnant. Relief that it wasn't cancer and sheer joy that we were having a baby. We were also in shock – when a midwife arrived to discuss birthing arrangements I thought I was dreaming. In hindsight I'd had other signs, but put morning sickness down to a virus and tiredness down to being busy." ▶

Allison had double-checked with doctors that she would never conceive naturally at the age of 30 after marrying her husband Richard. She told the *Daily Mail*: "We'd already given up all thoughts of having a baby ... But it was still terribly sad when tests confirmed I'd definitely gone through the menopause and that I'd never be a mum or make Richard a dad. He gave me a hug and said perhaps being parents wasn't for us."

After focusing on leading active lives as a childfree couple, they were delighted to find out that the doctors had been wrong. Allison woke up with contractions just twelve days after being told she was pregnant and subsequently gave birth to a baby girl weighing 6 lb 4 oz. Sophie is now 16 months old and her parents still can't believe their luck. Allison said: "Doctors have no idea why so many years after going through the menopause I suddenly conceived. Since her birth I still haven't had a period, so while we'd love another baby, it might be that she is our only child. We are just enjoying our precious daughter – she is the miracle baby we never thought we'd have."

Doctors normally advise women to continue using contraception for one year after their periods stop if they do not wish to fall pregnant.

BRITISH FERTILITY SOCIETY ANNUAL MEETING

Report by Dr Brianna Cloke

Fertility 2015 was a large conference held between 7 and 9 January 2015 in Birmingham. It was organised jointly by the British Fertility Society (BFS), the Association of Clinical Embryologists (ACE) and the Society for Reproduction and Fertility (SRF). There was also input from the Royal College of Nursing (RCN) and the British Infertility Counsellors Association (BICA). It was one of the BFS's largest conferences so far, with over 510 delegates. International speakers discussed cutting-edge research and new innovations and it proved to be an excellent platform to allow professionals to share information.

The meeting was opened by an inaugural lecture by Dr Sue Avery, focusing her talk on the importance of technological advancements in fertility treatment, as well as the emerging moral and ethical concerns in this area. She ended the lecture by acknowledging the legacy of patients who could not have had families without such treatment. There were multiple sessions throughout the three days focusing on all aspects of fertility including sessions on sperm, genetic screening and embryo implantation. Of particular importance to Daisy members was a session dedicated to egg development within the ovaries. At the moment there are no methods to harvest eggs from women with POI, but it is hoped that individual small advances in research will lead to an eventual breakthrough.

The BFS is a national multidisciplinary organisation representing professionals practising in the field of reproductive medicine. Dr Allan Pacey has been the Chair for the last three years and has just handed over the reins to Professor Adam Balen. Important changes that have taken place over the last year include an increase in public engagement. For the first time, the BFS attended the *Fertility Show 2014* in London and produced a dozen informative and evidence-based patient leaflets that covered topics such as 'Enhancing Success Rates of Assisted Reproductive Techniques'. They are hoping to be at the same event in November 2015.

The BFS will also be updating its website (www.britishfertilitysociety.org.uk) in due course. Under the 'Public Info' tab, useful factsheets about fertility can be downloaded for free. Important BFS statements can also be viewed under the 'Practice and Policy' and 'Press Office' tabs. Over the last year, these have included BFS's support of the Human Fertilisation and Embryology Authority (HFEA) report on adverse events in fertility treatment, such as side effects. Reassuringly, overall negative occurrences are low. The BFS will continue to work with the HFEA to learn from adverse events, to publish guidelines and to improve the quality of care provided by fertility clinics across the UK. A second important statement released last year covered the National Institute of Clinical Excellence (NICE) Quality Standards report on fertility treatment and was a call to end the postcode lottery for fertility treatment. The BFS is also increasing its presence within social media and posting welcome tweets on Twitter.

Lastly, within the remit of the BFS is a subcommittee dedicated to training health professionals. From this year, a new course titled 'Preserving Fertility in Cancer' will be made available. This is extremely important for Daisy Network members as cancer treatment is a significant known cause of POI.

All these aspects are important for the Daisy Network because in both the short and long term, our members will benefit. Meetings such as these foster and promote high-quality practice and research. Although not all the topics relate specifically to POI, advancement in fertility treatment is important. Furthermore, increasing awareness and optimising treatment to preserve fertility in cancer patients would be welcomed by all.

JENNIFER ANISTON CRITICISES "UNFAIR PRESSURE" ON WOMEN TO HAVE CHILDREN

In an interview with *Allure* magazine, Hollywood star Jennifer Aniston has spoken out about society's expectations of women when it comes to motherhood. Like other female celebrities without children – including Kylie Minogue and Cameron Diaz – the 45-year-old actress has been the subject of various rumours and jibes throughout her career. She told interviewers: "This continually is said about me: that I was so career-driven and focused on myself; that I don't want to be a mother, and how selfish that is."

Her criticism was not limited to the way women in the media spotlight are treated, however. She told the magazine: "I have a lot of friends who decided not to have children, who can't have children, or are trying but are having a difficult time. There's all sorts of reasons why children aren't in people's lives, and no one has the right to assume. It's rude, insulting, and ignorant. I don't like [the pressure] that people put on me, on women – that you've failed yourself as a female because you haven't procreated. I don't think it's fair. You may not have a child come out of your vagina, but that doesn't mean that you aren't mothering – dogs, friends, friends' children."

Aniston is not the only celebrity to have addressed this issue, which for many remains a taboo. Fellow actress Dame Helen Mirren talked to *Vogue* back in 2013 about the wide-spread expectations women are still confronted with. Women often face probing questions and a lack of sensitivity if they have not have children by their mid-30s. Mirren used to respond to such questions by claiming she had "no maternal instinct whatsoever", but admitted more recently that she had always thought she would have children one day before concluding: "It was not my destiny ... and I didn't care what people thought."

Figures suggest that fewer women are becoming mothers: 20% of women in England and Wales who reached the age of 45 in 2011 had never given birth, compared with 12% of the previous generation. In spite of this, childlessness – be it by choice or not – continues to trigger speculation and raise eyebrows all too often. Sue Fagalde Lick, author of *Childless by Marriage,* commented: "The expectation is that they will marry and have children. If they don't, everyone wants to know what's wrong with them."

MEMBER'S STORY

When I was 16 my GP prescribed me the contraceptive pill because I had heavy periods that were irregular. I was on it for five years and at 21 I decided I'd come off it hoping that my periods might have regulated by then, but actually nothing happened: no periods, nothing. My GP advised me not to worry and to wait six months and said we'd reassess the situation then. Six months later and still nothing, so I went back to see my GP. I was referred to a gynaecologist, who ran lots of tests. I had five or six appointments spread over a year and at my last appointment I saw a different gynaecologist, who blurted out: "Of course because you're going through a premature menopause and can't have children we're going to put you on HRT."

I've never really found GPs to be helpful because they're always so shocked.

"What?" She looked stricken and said she thought I'd been told. I felt embarrassed, very uncomfortable and also sorry for the gynaecologist.

She said my diagnosis was non-specific POF [now usually referred to as POI] which meant that my reproductive life had come to an end. What a shock. I was very young and it didn't sink in. I was 23 then. It took days before I told my mum and then I burst into tears. I tried to work it all out. I think I buried it for years, because I wasn't thinking about having a family. It was only when I met my husband that I thought about it more.

I'm nearly 40 now and I've been on HRT since my diagnosis and have never had any problem with it, though recently I've been having migraines and so my dose has been reduced.

I didn't get any help or advice but because I was so young I didn't understand the implications at the time. It wasn't until I got married that the diagnosis hit home. Looking back, I think it could have been discussed with me in a better way. It was shocking.

Since then, I've never really found GPs to be helpful because they're always so shocked. Whenever I ask for HRT they query my age.

I sometimes feel my girlfriends won't talk to me about children for fear of upsetting me.

Generally I'm good at dealing with the hand I'm dealt. It is what it is. I can't change it. I've mostly been pragmatic about my diagnosis. It's only in the last four years, when all my friends had babies, that I've felt affected. I joined Daisy to help myself. I know there's no point in being upset, but everyone I know has children now and that's really changed everything. I sometimes feel my girlfriends won't talk to me about it for fear of upsetting me, and I find that frustrating and upsetting. I have good years and bad years. I have my own business too and I can crack on and do that because I don't have a family.

Pound the Tarmac for Daisy

We have paid for a team of six runners to take part in the British 10K London Run on Sunday 12 July 2015. This means you can enter the event for free in return for raising funds for Daisy. Described as "the world's greatest road race route", the run will take you past some of London's most famous landmarks, giving you a unique chance to combine sightseeing with running!

You don't have to be a budding Olympian to take part – you just need to be able to complete the distance in less than two hours. So if more exercise was one of your new year's resolutions, why not start training today? There are lots of inexpensive running apps for smartphones which will gradually build you up to the full 10k. If you already run 5k regularly, you could be doing 10k in as little as nine weeks! Even if you're a novice, you could reach 10k with about 14 weeks of training three times a week.

For more details of the event, visit www.british10klondonrun.co.uk. The registration deadline is 7 July. There is no minimum fundraising requirement. Please email membership@daisynetwork.org.uk if you would like to take part. This is the last time we'll be offering free places for the foreseeable future, so make the most of it!

FREE COUNSELLING FOR DAISY NETWORK MEMBERS

Tele-counselling: help is only a phone call away

Tele-counselling is our scheme offering the chance to have half an hour of counselling over the phone with Chrissie Hosking. We offer this service free of charge to our members. The Daisy Network pays Chrissie for her time.

24 February, 24 March, 28 April
Sessions at 6.30, 7.15 and 8.00pm.

Send your name, address and phone number, either to the PO Box or by email to daisy@daisynetwork.org.uk. A slot will be allocated to you and Chrissie will call you.

POI (Young Menopause) FORUMS

Come along, meet up, share ideas and experience

Northwick Park Hospital
9.30–10.30am
5 March, 2 April, 7 May, 4 June, 2 July, 3 September

ALL WELCOME
The forums include a chance to meet with a member of the hospital's multi-disciplinary team for questions and answers, such as our specialist GP, specialist nurse or specialist pharmacist. They are open to everyone who has experienced POI. You should ideally be aged under 40 (and definitely under 45). There is no lower age limit.

Please put the dates in your diary and feel free to turn up. Or, if you prefer, contact Dani (who facilitates the forums) in advance at: d.singer@nhs.net or call and leave a message on 020 8235 4034.

Venue: Northwick Park Hospital
Gynaecological Outpatient Department.
(Please ask at reception then wait in the waiting area)
Watford Road
Harrow
HA1 3UJ

DAISY NETWORKERS

The networkers are members of the Daisy Network who are happy to take phone calls from other members. You don't need a particular reason to call – they are here to offer a friendly ear. You might have a query you don't want to trouble your doctor with or you might just feel a bit down. Please note that these numbers are for members only. Please do not pass them on to anyone else without the prior consent of the networker concerned.

MEDICAL AND SURGICAL

Angela, Kent
POI in 30s following cancer treatment.
01959 561 620, early evening.

Jasbir, Hertfordshire
Ovarian cancer at 21. Three children. POI at 32, then problems with HRT, then hysterectomy. Implant.
01462 629 463, evenings and weekends.
j.jaswal@ntlworld.com

Sarah, West Midlands
Total hysterectomy, uses HRT implants. No children.
07894 033 315, any time.
first55@aol.com

MISCELLANEOUS

Gemma, Northern Ireland
POI at 33, now 44. Spontaneous pregnancy in 2004.
02838 343 291, after 6pm.
gemma@gemma03.orange-home.co.uk

OTHERS' POINTS OF VIEW

Brian, Gloucestershire
Egg donation and psychological impact.
07802 490 563, any time.

Martin, Hampshire
Unsuccessful IVF. Adopted two children.
02380 849 602, after 7pm.
martin.c.hill@sky.com

TEENAGE DIAGNOSIS

Joyce, Fife
POI at 16. Successful and unsuccessful egg donation attempts.
01577 830 067, 7–9pm Mon–Fri, or any time at weekends.

Lisa, Northumberland
POI at 14, now in 30s. Successful egg donation.
01670 514 750, any time.
lisajonathan2001@yahoo.co.uk

Louise, Somerset
POI at 17, reason unknown. Takes combined Pill as HRT.
07816 399 203, after 7pm but not Tuesdays.
louise.k.baker@googlemail.com

EGG DONATION

Caroline, West Midlands
Diagnosed at 32, now 39. Successful egg donation in USA. Positive experience of HRT.
01926 733 411, after 7pm.
c.kuzemko@yahoo.co.uk

Karen, Wiltshire
POI in early 30s. Been on HRT for 12 years without problems. Successful egg donation – twins.
01985 211 494, evenings after 7pm.

Pamela, Surrey
POI due to resistant ovary syndrome. Successful egg donations.
0208 669 0508, 7–9 pm.
pa1hilton@btinternet.com

Jane, Hertfordshire
POI at 28. Successful egg donation. Reasonable success with HRT.
01727 370 723, any time.
janehussell@hotmail.com

Nicola, Worcestershire
POI at 35. Successful/unsuccessful egg donation abroad. Takes HRT.
01905 457 480, evenings after 7.30pm and any time at weekends.
armpete2@yahoo.co.uk

ADOPTION

Jacqueline, Devon
POI at 34. Four failed egg donations. Adopted two siblings. Spontaneous return of periods then normal pregnancy. Rediagnosed as resistant ovary syndrome.
01752 290 648, 7–9pm Mon–Fri and any time at weekends.
jacquelinehouslander@gmail.com

HRT

Kate, Cheshire
POI at 28, now early 40s. No children. Positive about HRT and life post-menopause.
07974 754 901, any time.
km_palmer@btinternet.com

Patricia, Roxburghshire
POI in early 30s, now in 40s. Single. Difficulties with various types of HRT. Interested in bone health (has osteopenia).
01573 224 604, 5.30–7pm

Thea, Kent
POI at 27. Conceived naturally. Problems with HRT, especially tiredness.
01795 538 014, 6–8pm

Jemma, Kent.
POI at 26, reason unknown but autoimmune in close family. Two young children. Takes HRT.
07977 464 682, after 5 pm weekdays and Saturday only.
jemma.crisp@btinternet.com