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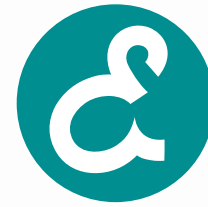
Supporting patients

**Annual conference 2018
workshop**

Chair: Kate Brian

www.hfea.gov.uk





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The importance of patient support

Dr Sue Avery
Birmingham Women's Hospital

www.hfea.gov.uk





**Human
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Patient support

Ruth Wilde

Infertility Counsellor and Authority Member

www.hfea.gov.uk



I have a dream.....

**The
Guardian**

Jemma Kennedy, author of play Genesis Inc...reflecting on her personal experience of fertility treatment
February 2018

“It is a very charged time and I came out of the experience feeling ~~brutalised~~ **totally cared for**. It was nothing physical, it was the attitude of the sector ... It felt like it was all about ~~money~~ **me**,” she said.

“It was an emotional time, but there was ~~no~~ **good accessible** counselling. “~~Nobody~~ **Somebody** sat me down and said: ‘Have you really thought about why you are doing this? What are the options? Where are you with your partner? Can you afford it? What’s going to happen if it doesn’t work?’ It all just felt like a ~~business transaction~~ **really-caring environment**, and that’s what I felt was ~~brutal~~ **supportive**.”

HFEA strategy 2017–2020

Aim: improve the emotional experience of care before, during and after treatment or donation.

We want:

- clinics to acknowledge how emotionally difficult infertility and treatment can be, and act on this
- an improvement in the experience of treatment, with minimal emotional harm
- better support for donor conception treatment
- support from the clinic after treatment to become the norm.

We will:

- define ‘good support’, including for donor conception treatment
- make excellent support a core message
- focus more on support at inspections
- seek feedback on the quality of support and the emotional experience of care.

What's the harm?

Sadly, we can and do cause some avoidable harm through clinic policies and procedures – it's usually about leadership not individual culpability.

- the way we schedule appointments
- being opaque about costs
- offering counselling to tick a box
- inaccessible counselling in terms of cost and availability
- the amount and type of information we give them
- not managing their expectations
- not including partners in decision making and consultations
- not following them up after bad news
- not admitting to our mistakes
- making assumptions about what support they do or don't need.

We don't need to reinvent the wheel...

Human Reproduction, Vol.0, No.0 pp. 1–11, 2015

doi:10.1093/humrep/dev177

human
reproduction

ESHRE PAGES

ESHRE guideline: routine psychosocial care in infertility and medically assisted reproduction—a guide for fertility staff†

S. Gameiro^{1,*}, J. Boivin¹, E. Dancet^{2,3}, C. de Klerk⁴, M. Emery⁵,
C. Lewis-Jones⁶, P. Thorn⁷, U. Van den Broeck², C. Venetis⁸,
C.M. Verhaak⁹, T. Wischmann¹⁰, and N. Vermeulen¹¹

¹Cardiff Fertility Studies Research Group, School of Psychology, Cardiff University, CF10 3AT Cardiff, UK ²Leuven University Fertility Centre, University Hospitals Leuven, 3000 Leuven, Belgium ³Center for Reproductive Medicine, Women's and Children's Hospital, Academic Medical Center, University of Amsterdam, Amsterdam 1105 AZ, The Netherlands ⁴Department of Psychiatry, Section Medical Psychology and Psychotherapy, Erasmus MC University Medical Centre, Rotterdam 3000 CA, The Netherlands ⁵Centre for Medically Assisted Procreation—CPMA, CH-1003 Lausanne, Switzerland ⁶Infertility Network UK, East Sussex TN40 1JA, UK ⁷Practice for Couple and Family Therapy, 64546 Moerfelden, Germany ⁸Women's and Children's Health, St George Hospital, University of New South Wales, NSW 2217 Sydney, Australia ⁹Department of Psychology, Radboud University Medical Center, 6500 HB Nijmegen, The Netherlands ¹⁰Institute of Medical Psychology, Centre for Psychosocial Medicine, Heidelberg University Hospital, 69115 Heidelberg, Germany ¹¹European Society for Human Reproduction and Embryology, 1852 Grimbergen, Belgium

*Correspondence address. E-mail: gameiros@cardiff.ac.uk

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STUDY QUESTION: Based on the best available evidence in the literature, what is the optimal management of routine psychosocial care at infertile and medically assisted reproduction (MAR) clinics?

ESHRE guideline

This is the first guideline offering evidence-based and good practice recommendations to all fertility staff about how to implement routine psychosocial care at fertility clinics.

E.g.

- Interventions should be tailored to meet needs of individuals, and to different times pre, during and post treatment cycles.
- Counselling is a suitable intervention for those that need it and individuals value the offer of it , but it isn't the only intervention.
- One of the main reasons people do not comply with continuation of treatment after one or more failed cycles is the psychological and physical burden of treatment.
- Provision of routine psychosocial care is every clinic staff member's responsibility.

HFEA role

- To produce practical guidance for UK clinics on how staff, systems and processes can support patients better, incorporating some of the recommendations from ESHRE guideline i.e. turn theory into practice.
- Support all clinics to meet the needs of their patients and donors, and their partners where applicable, through training and provision of written resources.
- To collaborate and consult with fertility sector professional organisations regarding best practice.
- Continue to require clinics to use intelligence from feedback mechanisms to improve the patient experience.
- Inspect clinics against new Code of Practice requirements.
- To work with BICA to ensure clinics' counselling services are meeting patients' needs.

The story so far....

HFEA conference 2017

Workshop on emotionally safe treatment:

- Prof. Jacky Boivin (Cardiff University) presented research evidence on patient experience and the need for psychosocial interventions.
- Anya Sizer presented Fertility Network UK/Middlesex University patient survey results.
- HFEA presented a draft pathway for support interventions during a treatment cycle.
- You gave us your feedback.

2017/18

- HFEA strategy
- Draft Code of Practice updates and workshops
- Started collaboration with BICA

2018/19 plans

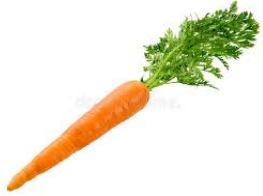
- Code of Practice Update: Patient support coordinator
Patient support policy
Quality indicators
- Engagement with professional organisations.
- Produce HFEA guidelines on patient support.
- Regional workshops for clinics in conjunction with BICA.
- Webinar seminars for counsellors.
- Production of written resources available for download from HFEA website for clinics and/or patients.

HFEA guidance

‘How to’ examples:

- patient support policy – what should go in this?
- quality indicators – what can be measured?
- patient support co-ordinator – what is the role?
- leadership qualities and actions
- emotional support pathway – showing recommended interventions at different stages of treatment
- assessment of patients at initial visit – how?
- online support hub – what information would be useful?
- short training seminars for staff – on what? How?
- gathering intelligence – patient feedback mechanisms and acting on them
- counselling service – best practice.

Why bother?



(It's the right thing to do)

- Happier patients more likely to return for recommended treatment and crucially more likely to want to stay at your clinic.
- Better feedback ratings both on HFEA website and through patient feedback questionnaires.
- Better word of mouth comments = more patients.



- Inspection – this is not law, so can't be mandated by HFEA – i.e. you won't have your licence revoked for not doing this. However, you will be inspected against compliance with the Code of Practice and the best practice guidelines

Rw.counselling@gmail.com
Anna.Coundley@hfea.gov.uk

www.hfea.gov.uk



Making patients heard: The male experience of infertility

Dr Esmée Hanna

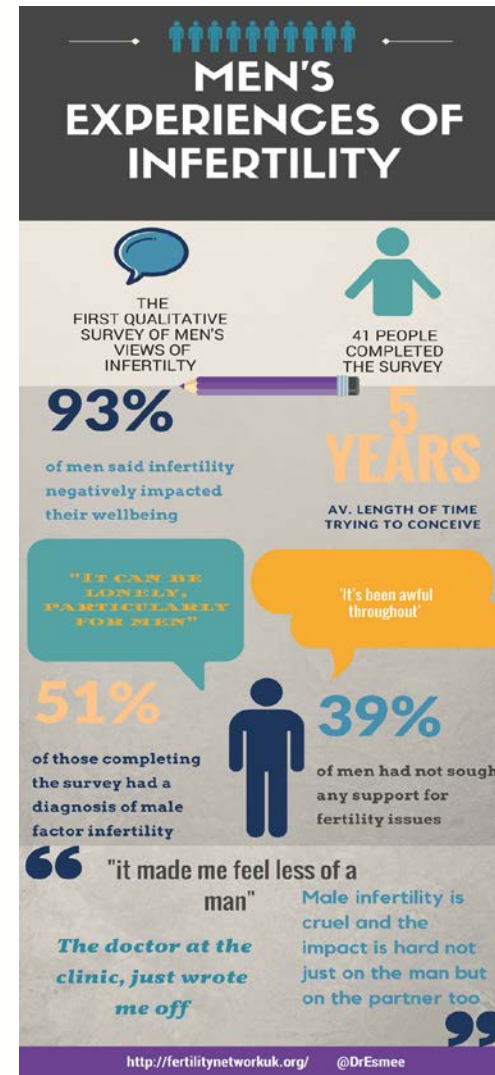
Centre for Health Promotion Research, Leeds Beckett University

Male Infertility

- Men routinely absent from discussions around fertility and reproduction (Culley, Hudson and Lohan, 2013; Lohan, 2015; Inhorn, 2009; Barnes, 2014)
- Yet 1 in 6 couples will experience infertility and of these 40 per cent of fertility issues are male factor, 40 per cent female factor and 20 per cent either unexplained or a mix of male and female factor issues
- Fertility and reproduction seen routinely as ‘feminised’ and as ‘women’s issues’ which marginalises men and burdens women
- Traditional their role in relation to fertility treatment is around playing the ‘sturdy oak’, ‘emotional rock’, or ‘silent partner’

Men's experiences

- Men who have experienced infertility suggest it impacts all aspects of their lives, including relationships, their work and career, as well as their own wellbeing
- *'It cant be lonely particularly for men'* (survey respondent)
- Infertility can be highly emotive experience, that is very distressing and which can often pose a crisis in the lives of those going through it
- Evidence about men's feelings and experiences have however been lacking from research into fertility....



Our study

- Spring/Summer of 2017 conducted a qualitative questionnaire with men about their experiences of infertility
- First time this method had been used- captures men's own words to open-ended questions and is anonymous
- Had 41 respondents, totalling around 25,000 words
- Asked men about key aspects of their lives including work, relationships, finance, emotions, medical settings and the impact or experience of infertility of these
- Mostly respondents were from the UK but some were international

Men's experiences of healthcare settings

- **Experience of healthcare professionals**
- Men reported feeling excluded and marginalised by the attention and focus being directed towards their female partners
- ***'Fertility treatment needs to become less female-centric'***
- Some participants highlighted a lack of sensitivity among clinical staff about the experience or news that people were receiving within fertility clinics
- Men perceived a lack of emotional support services provided by health care professionals and the fertility clinics they encountered
- ***'Fertility clinic just told us they could not do anything...if it is a male they write them off'***

Men's support needs

- 39% of respondents had not sought or had any other support for their fertility issues, demonstrating that a large proportion of men are potentially not receiving support (although some may not feel they require any additional support)
- support services for those contending with fertility issues are often aimed specifically at women
- 'I set up my own [internet forum] due to lack of support groups for men'
- Men advocated better support for men
- Forums, online groups, more counselling and male only support groups were all suggested as possible options for support that would like to see

Summary

- Vital that we include men's voices within societal conversations around infertility and within fertility treatment- they are patients of fertility clinics
- Research can be a useful mechanism for amplifying men's voices but requires that we translate these voices into practice
- Idea that men are reluctant to speak about infertility has not been my experience as a researcher- giving men the opportunity to have their say and be included is vital for ensuring they feel included and supported
- Support for men could take a variety of forms, but need to ensure that we make support gender sensitive to ensure that men are not only heard but adequately supported

CARE Fertility - Patient Support in Practice

Improving Patient Care through Emotional and Social Support

Kelly Da Silva - CARE Support Coordinator & Founder of The Dovecote.org



The Aim:

The aim of our 'CARE *Together Support Package*' is to establish additional support structures for our patients in a commitment to making their fertility journey easier.

Why was this developed?

- *From a **psychological, emotional and social perspective** we know how isolating and gruelling the impact of fertility treatments can be on a person or couple.*
- *Latest research* shows “A stark and distressing picture’: emotional, social & economic impact of fertility problems far greater than previously recognised”*
- *Patients recognise and feel that the fertility journey is more than just a medical process.*

*Fertility Network UK with Middlesex University (Oct, 2016)

Support events

Supporting you on your journey.

When you're going through **fertility treatment**, it can be a daunting process. We understand that there may be things you would like to talk about with other people also going through **IVF**.

Our support events

We have a range of monthly patient support events which are accessible for all patients, regardless of your stage in the IVF journey.

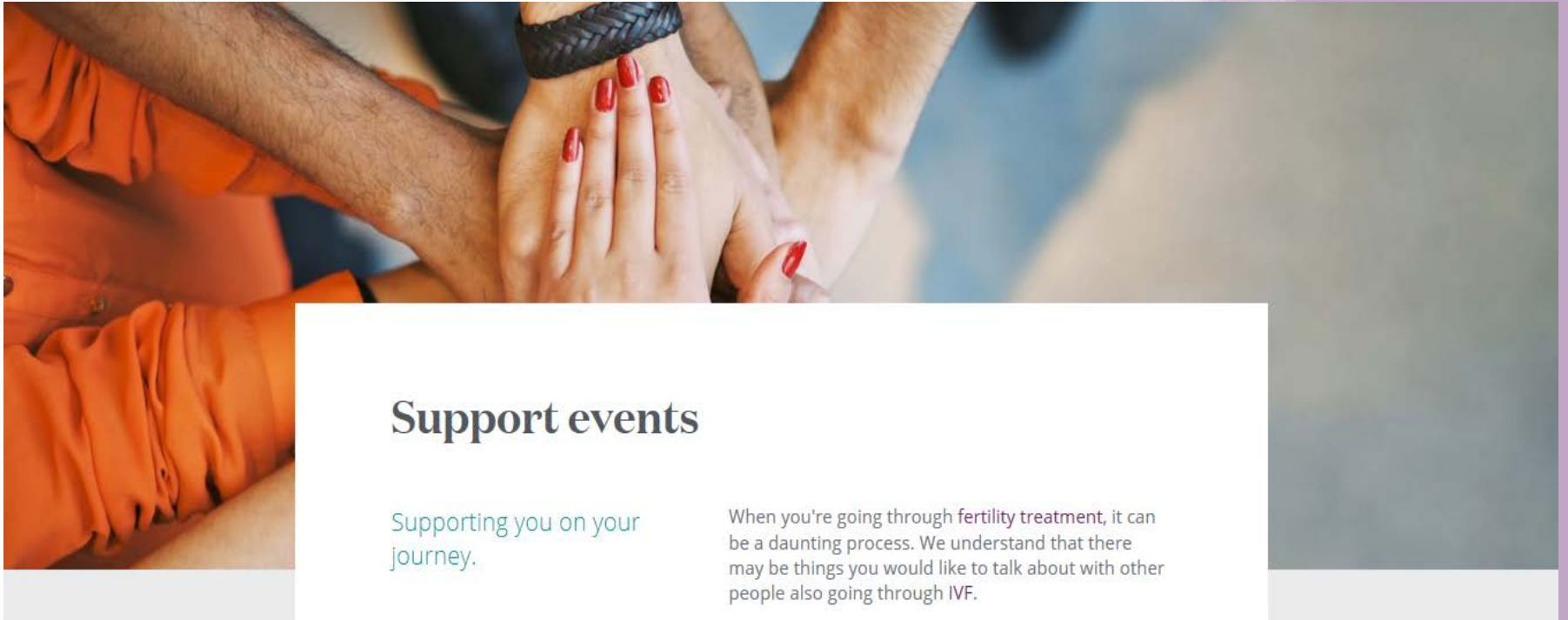
Our monthly events include our Fertility & IVF Support Group at **CARE Nottingham** and **CARE Sheffield**, Online Skype Webinars, 'Walk N Talk' Events and the CARE Buddy System.

For more information & to book your place on any of the events below, please e-mail Kelly, our CARE Support Coordinator: enquiries@carefertilitysupportgroup.co.uk



Kelly Da Silva
CARE Support Co-ordinator

Kelly Da Silva, our CARE Support Co-ordinator facilitates our support sessions. As a former patient, founder of a support organisation, a practitioner of Neuro-linguistic Programming (NLP) and Emotional Freedom Technique (EFT) Therapist, she is passionate and specialises in working with people at all stages of their fertility journey.



Support events

Supporting you on your journey.

When you're going through fertility treatment, it can be a daunting process. We understand that there may be things you would like to talk about with other people also going through IVF.

CARE Support Meetings 7-8pm (in the clinic)

CARE Nottingham Support Meetings

- Thursday 22nd February 2018
- Thursday 22nd March 2018
- Thursday 26th April 2018
- Thursday 31st May 2018
- Thursday 28th June 2018

Join us at 7 - 8pm in your CARE Fertility clinic to meet face to face with others going through the IVF journey. These meetings are a chance to meet with other people undertaking IVF and get further emotional support from others who really understand the process.

CARE Online Support Meetings (via Skype) 8-9pm

Support via Skype



Meet other people going through the IVF journey in the comfort of your own home and learn some useful techniques for dealing with the emotional aspects of your IVF journey.

Each session will have a theme and input from either Kelly our support coordinator or guest speakers. There will be opportunities to talk about your experience, if you wish, and ask questions about dealing with the emotional and social aspects of IVF.

- Wednesday 7th February 2018
- Wednesday 14th March 2018
- Wednesday 11th April 2018
- Wednesday 2nd May 2018
- Wednesday 6th June 2018

Walk 'n' Talk Events - at Strelley Woodland, Nottingham 10.30am - 1pm



Get your walking boots on and join us once a month for a gentle 5K Walk 'n' Talk at the lovely Strelley Park in Nottingham (close to CARE Nottingham). The walk starts at 10.30am and afterwards we're meeting for coffee at The Mulberry Cafe in the grounds - it's our treat. If you don't want to walk you can still have coffee with us - see you there at 12 noon.

Walk 'n' Talk Therapy provides a unique method of support. Instead of a formal therapy approach, these sessions are relaxed and informal, taking place whilst walking in the English countryside. This method is perfect if you want to incorporate exercise and fresh air whilst gaining support and connecting with others going through the IVF journey.

- Sunday 18th February 2018
- Sunday 18th March 2018
- Sunday 15th April 2018 @ Chatsworth House
- Sunday 20th May 2018
- Sunday 24th June 2018 @ Chatsworth House



CARE Buddy - Peer to Peer Support System

Who can be involved?

CARE Buddy is for anyone going through IVF and/or egg freezing processes, regardless of your personal circumstances, relationship status or stage of your journey.

How do I register to 'Opt in'?

You simply need to register your interest by either emailing our CARE Support Coordinator at: enquiries@carefertilitysupportgroup.co.uk with our reception team or CARE counsellors who will pass on your details.

How will you be matched with a CARE Buddy?

Once you have registered to the 'Opt in' scheme, you will be asked for some basic information and preferences so we can find you the most suitable match. Our Support Coordinator will carefully select you a CARE Buddy whose stage in the IVF process and circumstances fit your preferences best.

What happens once I have been matched with my CARE Buddy?

Once you have been suitably matched with a CARE Buddy, you will be given your Buddy's preferred method of contact and details to enable you to connect with one another outside of the clinic. You are free to make contact in the most convenient way, many choose; text, messenger or WhatsApp whilst others call or have a meet up.

CARE Buddy

What are the benefits of having a CARE Buddy?

CARE Buddy is an opportunity for you to both receive and offer help and advice to other CARE patients going through the IVF journey. It offers you both:

- The opportunity to receive support and comfort that you are not alone in the journey you are undertaking.
- A chance to offer your own invaluable support to others based on your own experiences.
- A safe space in which to alleviate any potential anxieties and worries by sharing your story and hearing other patients' IVF experiences.

Who can be involved?

CARE Buddy is for anyone going through the IVF and/or egg freezing processes, regardless of their personal circumstances, relationship status or stage in the IVF journey.

How do I register to 'Opt in'?

To become a CARE Buddy, simply register your interest by either emailing our CARE Support Coordinator at enquiries@carefertilitysupportgroup.co.uk, registering with one of CARE's reception team, or feel free to chat to one of our Counsellors at your CARE clinic.

How will you be matched with a Buddy?

When registering as a CARE Buddy, you will be asked for your preferences so we can find the perfect match for you. Our CARE Support Coordinator will carefully select you a CARE Buddy whose stage in the process, and personal situation or circumstances, are ones that relate to you personally, so you can both get the most out of your time together.

What happens once I have been matched with my CARE Buddy?

Once you have been suitably paired with a CARE Buddy, you will be given your Buddy's preferred method of contact and details to enable you to connect outside the clinic at a mutually convenient time.



Who is our CARE Support Coordinator?

Kelly Da Silva facilitates all of our CARE Support sessions here at CARE Nottingham.

As a former patient, Founder of a support organisation, practitioner of Neuro-linguistic Programming (NLP) and an Emotional Freedom Technique (EFT)



Kelly Da Silva
CARE Support Coordinator

Therapist, Kelly specialises in working with people at all stages of their fertility journey, and is extremely passionate about helping others.

What do our patients think about 'CARE Together' Support?...

“After feeling so isolated the opportunity to meet people in a similar situation was amazing.”

“It was reassuring to know that every emotion and thought is normal and that we are not alone.”

“Thank you, this alone has made a huge difference to my mindset and confidence.”

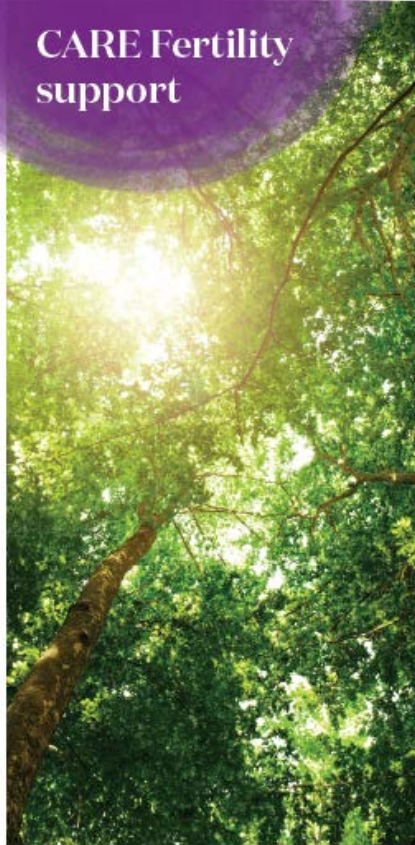
CARE Buddy ~ Matching Matrix

The following matrix can be used to match patients who have 'opted in' for the CARE Buddy Peer-to-peer support.

N.B. Place names of patients in the relevant box to match potential buddies

	Starting treatment / New to CARE Fertility	1-3 Failed Treatment Cycles	More than 3 Failed Treatment Cycles	Using donor egg / sperm	Considering other options / Adoption	Considering stopping treatment
Heterosexual						
Single						
Same sex relationship						

CARE Fertility support



CARE Fertility Support

Online Support Meetings

Via Skype • 8pm - 9pm

Wednesday ~~4th~~ April • 2nd May
• 6th June

Meet other people going through the IVF journey in the comfort of your own home, learn some useful techniques for dealing with the emotional aspects of the IVF process and share experiences with one another.

Support Meeting

CARE Nottingham • 7pm - 8pm

Thursday 26th April • 31st May
• 28th June

Join us at CARE Nottingham to meet face-to-face with others who are also going through IVF treatments.

Walk 'n' Talk Events

Strelley Woodland, Nottingham

• 11.00am - 12.30pm

Sunday 20th May

Chatsworth House, Bakewell

• 11am - 12:30pm

Sunday 15th April • 24th June

Come and join us for a gentle 5k walk through the countryside, or feel free to meet us at the Mulberry Cafe at 12-1pm and let us treat you to a coffee.

CARE Buddy

Our CARE Buddy support system provides the perfect opportunity for you to both receive and offer help to others who are also going through the journey to creating a family.

This peer-to-peer support method is facilitated by CARE's Support Coordinator and our Counsellors who will ensure you are carefully matched with a buddy who is at a similar stage in the treatment process to you. You will then be able to connect with one another and share your experiences during, and following on from, your treatment.

This is a great opportunity to:

- Receive support and reassurance throughout your individual IVF journey.
- Offer your own invaluable advice to others based on your own experiences.
- Alleviate potential anxieties and worries by sharing your story and hearing other patients' experiences.



What our patients says:

"After feeling so isolated, the opportunity to meet people in a similar situation was appreciated"
CARE Patient

"After each 'Walk and Talk' I feel like I can see clearer and have the strength to keep plodding on with treatment. It makes me thankful that I chose CARE as they clearly value the 'oh so important' mental health aspect of dealing with the challenges of infertility."
CARE Patient

"Chatsworth made an idyllic spot for a walk and talk. It was brilliant to chat to girls in a similar situation and soak up the majestic views at the same time: a nice spot of mindfulness! I now feel ready to get cracking on the next round!"
CARE Patient

"It was reassuring to know that every emotion and thought is normal and that we are not alone"
CARE Patient

What our patients say:

"Having only recently found out that I would be preparing for IVF, I had a thousand questions buzzing through my head. Thanks to the CARE support group, the wonderful ladies I met on our Chatsworth walk completely reassured me with their anecdotes and advice and I left feeling like a weight had been lifted from my shoulders! Since then the group have been incredibly supportive and I can't wait for our next outing!"

CARE Patient

"Thank you, this alone has made a huge difference to my mindset and confidence"

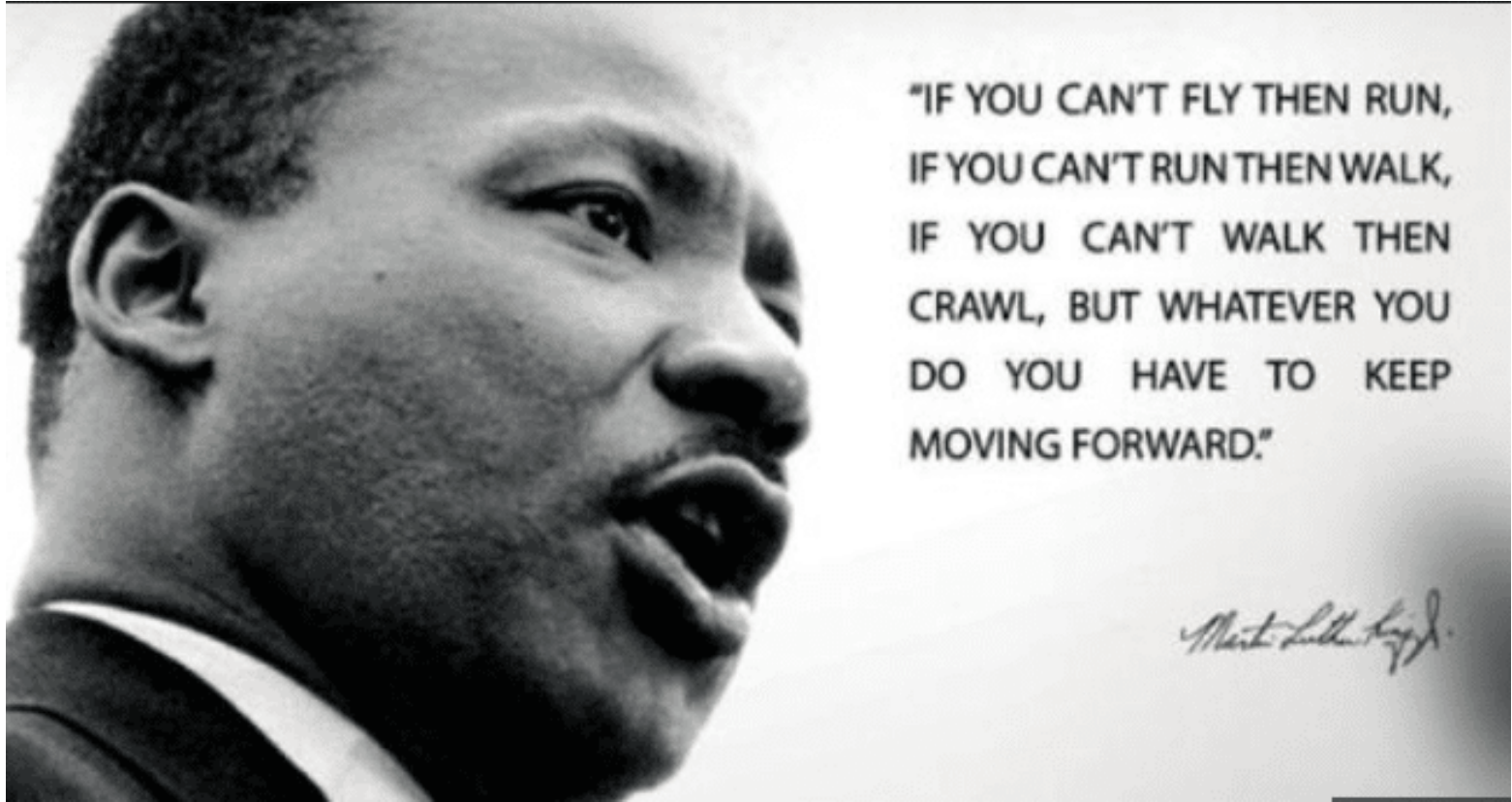
CARE Patient

Findings:

- *Patients are highlighting the value in this care.*
- *Patients feel more supported & less isolated.*
- *Patients feel comforted that they are going to be looked after and there is support whatever their outcome.*



carefertility.com



"IF YOU CAN'T FLY THEN RUN,
IF YOU CAN'T RUN THEN WALK,
IF YOU CAN'T WALK THEN
CRAWL, BUT WHATEVER YOU
DO YOU HAVE TO KEEP
MOVING FORWARD."

Martin Luther King Jr.

Discussion

1. What are you now doing well to support patients – any ideas you can share?
 2. What are you worried about/excited about (regarding HFEA strategy on patient support and implementation)?
 3. What have we got right/wrong?
 4. Barriers to implementation in your clinic? How to overcome them.
 5. How can you be an effective leader (no matter what your role is in the clinic) regarding patient support?
- Anyone want to help – e.g. developing/commenting on written resources and guidelines?