

The Newsletter of the Nuffield Patient Group

Welcome!

There is no better way to start than with a big 'thank you' to Jeanette Costigan for sharing her personal breast cancer journey (see article, this page). Jeanette's honest article gives us all hope that we will be as strong as she is in dealing with cancer and living a happy and fulfilling life.

At a much more mundane level, it's the Blandford Fly season already, so on page 3 we have a few tips about how to manage if you are bitten.

Over on page 4, Christine Symon describes how patients can get involved in research if they wish, and the benefits that can come from that. The Nuffield Practice is currently thinking about taking part in some GP research, so stay tuned.

There is news from the Practice on page 5, along with another lovely, original cartoon from Tim Hughes, and on page 6 Sarah Chapman brings us the latest on nicotine replacement to help quit smoking. Enjoy!

My breast cancer journey By Jeanette Costigan

I was diagnosed with a 60 mm invasive lobular tumour in my left breast (estrogen receptor, progesterone receptor and human epidermal growth factor receptor 2 [HER2] negative) without lymph node involvement in June 2015. Fortunately, I found the lump myself (in between mammograms) and was able to get it detected quickly.

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My breast cancer treatment journey lasted 3.5 years, starting with various diagnostic tests and a therapeutic mammoplasty (lumpectomy), followed by adjuvant chemotherapy (September–December 2015), mastectomy (for clear margins in January 2016) and then 3 weeks of radiotherapy to the chest wall (May 2016) and excision of a seroma cavity (June 2017).

The chemotherapy was not a pleasant experience and it knocked the stuffing out of me, so when it came to a choice of mastectomy with or without immediate reconstruction, I opted for a straight mastectomy. I just wanted to get rid of



Continued overleaf

the offending breast, forget all about it and get on with my life. I decided I would be fine with a prosthesis, wearing a post-surgery bra and the right neck line. I believed that, if I looked normal in clothes, I would be fine.

I was prescribed and tried three different types of endocrine therapy: anastrozole, letrozole and tamoxifen. My oncologist worked quite hard at trying to convince me to take this; however, each one made me feel like a zombie and I decided I couldn't tolerate any of them. I made a conscious choice for 'quality' over 'quantity' of life. I hope I don't regret this decision. My oncologist blinded me with data that support women taking this endocrine therapy to ensure that their breast cancer doesn't return; however, the evidence wasn't powerful enough to get me to choose 'quantity' over 'quality'.

Throughout all my treatment, I saw the same oncoplastic breast surgeon and oncologist. This was a great comfort to me, as I felt that they had been able to get to know me a little and treated me like a person, not just a patient. During one or two of my routine follow-up appointments, my surgeon gently suggested that I may want to consider delayed breast reconstruction and right breast symmetrization. I said no initially; however, when she explained that I would be a good candidate for reconstruction with extended latissimus dorsi (LD) flap (using a muscle from my back) and an implant, and that she would be the one to perform the surgery, I agreed to go ahead. She had carried out the previous three rounds of surgery and I was happy with the results, as far as one can be in such circumstances. So, I had three more operations (in February 2018, April 2018 and July 2018). The last one was nipple reconstruction.

The final piece of the jigsaw was to have an areola tattoo, which I had in November 2018. I was finally signed off by my surgeon as having

completed the journey in January 2019, 2 weeks ago.

So now, 3.5 years after this journey began, I am a bit scarred, my hair has grown back (although not as thick as it was before I had chemo), I have tattooed eyebrows because they fell out during chemo and didn't really grow back, and I feel that I have returned to 'near' normal.

Reflecting on this whole experience, I would say that it wasn't as bad as it could have been. Cancer kills, and I am still alive. I am grateful for that. I feel blessed by the highly capable and talented medical professionals who treated me. My employer, my lovely colleagues and my family were wonderfully supportive and helpful during this experience and I am forever grateful for that too. They could have made it so much harder for me but instead they carried me through it.

I am also grateful for all the research and investment into cancer treatments, which has meant that people like me can now survive this nasty disease and I, for one, can pretty much get on with my life as if it never happened.

A word of advice for women – find out how to check your breasts for abnormalities and do it regularly; cancer caught early has a good outcome.

According to Cancer Research UK: 'Incidence rates for breast cancer are projected to rise by 2% in the UK between 2014 and 2035, to 210 cases per 100 000 females by 2035'.

A word of advice for men too. I am no expert of course, however, please don't be embarrassed or worried about going to your GP to get checked out if you have any unusual symptoms.

Again, according to Cancer Research UK: 'Prostate cancer incidence rates are projected to rise by 12% in the UK between 2014 and 2035, to 233 cases per 100 000 males by 2035'.

The Blandford Fly

A Blandford fly is a blood sucking black fly, they are about 2–3 mm in length. They give a nasty and painful bite during the summer months, particularly in May and June. The flies are typically found near areas of water and there has been a rise in the number of people severely affected by the bites in these types of areas, both rural and urban.

What to look out for?

The insects fly less than 0.5 m from the ground, resulting in bites to the lower limbs. These bites cause small to large blisters which can be up to 22 cm in diameter and purple lesions. The saliva from the fly can cause intense pain, local irritation, redness, swelling, joint pain and even a high temperature of 38°C and over.

Treatment

Local reactions can last for several days or longer, but can be symptomatically treated by over-thecounter products.

Antibiotics are rarely needed, although



scratching the irritated areas can rupture the skin, leading to infections.

To avoid being bitten by the Blandford Fly, especially when near rivers, stream and



grassland:

- cover up, covering legs and ankles
- \cdot apply a quality insect repellent
- · avoid swarms of insects.

If you do get bitten from what you think is a Blandford Fly, make sure you:

- \cdot clean the bite with soap and water
- do not scratch, as this may lead to an infection

 $\boldsymbol{\cdot}$ apply a cold press or ice pack to reduce redding and swelling

- take or use antihistamine tablets and creams
- \cdot take pain killers if needed
- \cdot cover large blisters with dry, non adhering dressing

Seek medical attention if the bite shows signs of swelling, is uncomfortable, red lines appear within the groin or armpit area, you have a persistent high fever, spreading redness or hotness around the bite (longer than 3 days). If you have anything more severe, seek immediate help (call 999).



St Mary's Church, Church Green, Witney

How can I make a difference?

By Christine Symon, NIHR Clinical Research Network, Thames Valley and South Midlands (CRN TV&SM)

One option you may want to choose is to take part in clinical research:

Clinical research is embedded throughout the NHS, including studies (the term I will use for clinical research in this article) based in a practice setting, known as primary care research. Central to primary care research are the patients of the practice. Participation in research studies is voluntary. Ask why a person gets involved and the reasons given are many – for some there is the opportunity to learn more about the illness they may have had for many years, for others it may be the chance to receive a treatment or type of screening for a disease not routinely available. Do not under-estimate the role of altruism either. Feedback from participants also highlights the enjoyment of making a difference.



"Patients value the additional time and information given to them when taking part in a research study and it can help them understand so much more about their health." Sarah Wytrykowski, Primary Care Research Nurse Lead, NIHR Clinical Research Network Thames Valley and South Midlands

"I really enjoyed participating in the study and the research nurse was supportive the whole way through. I'm so glad to have participated in helping medical research." Quote from a patient.

The focus of that 'difference' is providing the evidence that informs change in the dynamic environment of healthcare. Alongside the ongoing search for better treatments, primary care research conducted today will inform the work of NHS healthcare professionals in the future and how people will be able to look after their health.

Participant involvement varies, depending on the nature of the research question being addressed. These range from a 'light touch' one-off survey, through to the commitment of a double-blind, randomized controlled trial (where no one involved with the research is party to whether a participant is in an 'intervention' or 'control' group). Studies taking place within a practice setting are diverse, reflecting the allencompassing role primary care has within our healthcare system - diabetes, depression, asthma, chronic kidney disease, the management of high blood pressure and weight loss to name but a few. Studies taking place at a local hospital - or occasionally further afield - may also be an option, with an invitation coming via the practice.

Most primary care research comes from academic institutions, with the Nuffield **Department of Primary Care Health Sciences** (NDPCHS) at the University of Oxford an important contributor. It is supported by government funding from the National Institute for Health Research (NIHR) and the regulatory oversight of the national Health Research Authority (HRA), and the more locally based Ethical Committees. An individual practice will decide what studies they are able to support, with knowledge of their patient base an important factor in whether they think a study would work well for them. It can range from an occasional mail-out to patients inviting them to contact a hospital based study team if interested to learn more, to a practice with a large and mixed portfolio of studies.

For those practices that have done a lot of research over the years, members of the local CRN TV&SM Primary Care Research Nurse team (who come in to perform study visits on an 'as required' basis) have become familiar and friendly faces. Nurses from the NDPCHS Clinical Trials Unit, or members of a study team provide hands-on support too for some of their studies. Conducting research within primary care draws on the collaboration of researchers, the Clinical Research Network, the practice team and their patients.

How to get involved with primary care research

At a practice, promotional posters or leaflets displayed in a waiting room or on a waiting room

screen, a letter of invitation from the practice and a conversation with a nurse or doctor are the means by which potentially eligible patients are generally informed about individual studies.

Interested to know more about the wider picture of clinical research in the CRN TV&SM area?

Visit Twitter: @NIHRCRN_tvsm



Tim Hughes

From the Practice

Dr Leanne Abram will be joining the team on the 23rd April. She will be taking over Dr Ede's list and will work on Tuesday, Thursday and Friday.

Dr Ede has moved to Leicestershire to be closer to her boyfriend. We wish her all the best for the future.

Dr Rogers has left the Practice; we also wish her the best for the future.

Dr Laura Bennet joined us in mid-February and she has taken over Dr Rogers's list. She works on Monday and Tuesday. Dr Anna Smith will join us on the 1st July. She will work on Monday and Thursday and she will help to manage some of Dr Rogers ex patients.

Sarah Bright, who worked on the Duty Team alongside the paramedic Practitioners, has moved to Eynsham Medical Group.

We have three new Receptionists; Suzanne, Primrose and Rachael. They are settling in, and they are still learning, so please be patient with them!

Evídence Matters

by Sarah Chapman

I work for Cochrane UK, the UK hub of an international network of people working together to help people make informed decisions about health care. It does this through doing systematic reviews, which bring together the results of clinical trials to answer questions about what helps or harms in health care.

New evidence on nicotine replacement therapy to help smokers quit

Using more than one type of nicotine replacement therapy (NRT) to help you give up smoking increases your chances of success, compared with using one type only. That's the headline message backed by high quality evidence in a new Cochrane Review.

We already know that NRT can help smokers to quit. It does this by replacing the nicotine they are used to getting from tobacco, getting it to the brain through a variety of routes. NRT is available as sprays (into the nose or mouth), inhalers, gum, lozenges, tablets and skin patches. But which way is best?

A team from Cochrane looked for all the relevant research studies that could help answer this question. They found 63 trials involving 41,509 smokers (mostly adults) who wanted to quit. Most smoked at least 15 cigarettes a day at the start.

More is better

They found that people using a nicotine patch together with another type of NRT, such as lozenges, were more likely to quit smoking for six months or more than people using just one type of NRT.

Does the dose matter?

Using higher dose nicotine gum made successful quitting more likely than lower dose gum (4 mg of nicotine versus 2 mg). The evidence is less certain on doses of nicotine in skin patches, but higher dose nicotine patches (containing 25 mg or 21 mg) probably make quitting more likely than lower dose patches (15 mg or 14 mg).

Starting NRT before quitting may help

This is something we need more evidence to be sure about, but it seems that starting NRT before 'quit day', the day on which someone stops smoking, probably improves the chance of success. However, we still don't know how long it should be used for.

Is NRT safe?

NRT is considered to be safe, but little is known about how different types of NRT compare in terms of harmful effects. Most of the research studies didn't look at safety! Harmful effects that were reported were generally mild, such as skin irritation from patches.

The bottom line?

Lead author, Dr Nicola Lindson from the Nuffield Department of Primary Care Health Sciences, University of Oxford, UK said "This high-quality evidence clearly signposts that the most effective way to use NRT is to use a combination of two products at once, a patch and a fast acting form such as gum, nasal spray or lozenge. Quitting this way increases the chances of you stopping smoking altogether."

You can see the review in full at <u>www.thecochranelibrary.com</u>.

Lindson N, Chepkin SC, Ye W, Fanshawe TR, Bullen C, Hartmann-Boyce J. Different doses, durations and modes of delivery of nicotine replacement therapy for smoking cessation. Cochrane Database of Systematic Reviews 2019, Issue 4. Art. No.: CD013308. DOI: 10.1002/14651858.CD013308.

For further information about this newsletter, please contact:

Catherine Simonini, Practice Manager, The Nuffield Practice (<u>catherine.simonini@nhs.net</u>) or Graham Shelton, Editor (<u>graham.shelton@pharmagenesis.com</u>)

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