

# Keeping Well?

The Newsletter of the Nuffield Patient Group

Winter 2019 Issue 23

## Welcome!

It's rare for me to start with anything less than positive, but the early retirement of Dr Oliver Boland should not go unremarked. The service that he gave to all his patients was exemplary in every way, as much for the humanity and kindness he displayed every single day, as for his outstanding clinical ability. We wish him well, and sincerely hope that the care he and his family receive will be as good as the care he gave (see page 4).

Also in this issue:

- Living with a rare genetic disease (this page)
- Caring for carers, a contributed article from Guideposts (page 2)
- Another original cartoon from Tim (page 4)
- An update from the Practice about its new structure (page 5)
- The evidence about vitamin and diet supplements in dementia (page 6).

Don't forget, that we'd still like to recruit more patients, especially younger people, to our Patient Participation Group. Please contact Catherine Simonini if you'd like to join.

## *My genes make me ... me!*

*By Ellie Collins*

If I think back to my diagnosis 5 years ago when I was told I have a significant risk of breast, thyroid, uterus, kidney and skin cancer, to now when I live a 'normal', happy, fulfilled life where I embrace my Cowden's diagnosis with a positive, lucky outlook, it makes me realize life really can be what you make it!

Having received the diagnosis after my Dad was found to have the gene mutation means we have two gene warriors in our family, but really my unit (my amazing friends and family around me) are all warriors helping embrace life and the challenges it throws in a positive outlook. Our strength was highlighted around 4 years ago when both my Dad and I received the C word diagnosis for our thyroids. The biggest personal challenge I had was accepting that I had cancer. For around 6 months I said to people I had 'funny thyroids' and my real diagnosis was like a dirty swear word. But when I accepted this I then accepted everything about me, my Cowden's, my thyroid cancer, my big head (symptom of Cowden's), my skin lesions – it all makes my ditzy, disorganized, scatty self!



*Continued overleaf*

The next realization was after my cancer treatment when my genetics doctor listed all the areas of my body at risk of cancer and crossed out thyroid. Which cut the list by a quarter! My thyroid journey wasn't close to what some people go through with cancers, but I had battled it and got it off my list! Maybe this challenge of life with my genes isn't as hard as I thought it may be.

My third realization was when I started helping PTENUKI. Suddenly, I was not the only person with a list, and helping other people with my outlook helped me to accept my diagnosis and me for me! The power of people is amazing. I

don't read medical documents or leaflets because I don't know if that is going to be my outcome (no one knows when it comes to genes), but I read blogs, Facebook comments and listen to my PTEN friends as they are the ones living and breathing with a list!

My future looks amazing, I am marrying my best friend this year, I am happy in my career and have the best time with my family and friends. So my advice (if people want to hear it) – if you or someone you love gets a diagnosis to do with their genes, don't worry about the unknown, embrace every challenge and remember they are what makes you you!

### *Caring for carers; are Oxfordshire's hidden heroes getting the support they deserve?*

*By Alice Shorter, Fundraising and Engagement officer at Guideposts Trust.*

Across Oxfordshire, Doctors, Nurses, clinics and charities are supporting thousands of people with health issues, impairments, disabilities and long term conditions. They play a vital role in maintaining the health, independence and wellbeing of people in the county who need it most.

But there are also thousands of carers who give hours of support to these individuals. Family, friends, neighbours...whatever the relationship, there are an estimated 61,000 carers in Oxfordshire alone\*. It is estimated that 1 in 8 adults is a carer, half of whom are also juggling their care roles with paid work. However the significant demands of caring roles mean that 20% of carers are forced to give up paid work altogether.

With 50-hour working weeks becoming increasingly common and with little to no pay in some cases, carers are under a huge amount of pressure and I believe it is the role of the community to help support them and let them know how vital and appreciated they are. After all, carers save our national economy an estimated £132 billion per year. That averages out at over £19,000 per carer!\*\*

Although financial aid (such as the National Carers Allowance) is available, where can carers find the emotional support they deserve? Support can come in many practices and is personal to each individual. But I believe that basic support comes in three main forms.



**Peer Support** – From toddlerhood, our peer group plays a vital role in our lives. It is where we find friendships, guidance, inspiration, laughter, discussion. Our need for peer contact doesn't stop, but our time available to access it can reduce during certain periods of our lives.

We receive regular feedback from the carers of those we support saying that through attending groups and projects, they have regular access to their peer group. They are meeting other carers on a weekly basis and are finding true friendship through the experience that they share.

For us, it is a clear measure that we are doing something right amongst this growing community of people.

I believe that it is hard to truly understand the work another does without experiencing it yourself. A role such as a carer is a shining example, and to find a room full of other carers who understand the commitment, responsibility, emotions and challenges you face, must be freeing.

**Lights up** is an arts and memory club run by Guideposts Trust for people living with dementia and their carers. Running fortnightly in 4 locations, the club is designed to support those living with dementia through practical activities such as singing, music, art, poetry and movement. Carers can join each session for a cup of tea, a good chat and often (in my experience anyway) can be found singing and dancing along with the session leader. The smiles on faces are undeniable and the feedback, always positive.



**Respite** – I am in no doubt that the amazing people caring for their loved ones do so with colossal amounts of love and respect for them; a job where the reward level can be unrivalled. However, I am also in no doubt that these individuals need time off, time to focus on themselves, their families, a holiday, a lunch out, or simply time to tidy their own home. But not only do they need and deserve this time, they want the reassurance that whilst they're not with their loved one, they are still being cared for in a dignified and respectful way.

This is why it is essential that community groups exist that cater for people with mobility issues, disabilities, dementia (and other age-related conditions), long-term conditions and so on.

If individuals who require added support could go along to coffee mornings and social groups that cater for their condition, not only can they feel some independence, but their carer can steal some time away for a coffee with a friend, a wander around a book shop or time to do their food shop, knowing that their cared for are amongst supportive friends. The freedom, relief and reassurance that could bring a person are unmeasurable.

Coffee mornings and social groups are becoming more common. Ask your Local Authority to help you locate one near you.

Guideposts are launching a Dementia-friendly Supper Club in the Spring – for more information, please call them on 01993 893560.

**Information, Advice and Guidance** – by giving carers access to tailored information and guides, carers can create a wider self-support network on their own terms, in their own time. Local authority newsletters, websites, community groups and leaflets can help carers find practical tips, hints and support avenues to design and access their preferred support. Oftentimes, we hear that simply having more information on what help is available can offer relief and support to someone caring for a loved one.

For your copy of our “Getting Support as a Carer” booklet, please contact Guideposts on 01993 893560 and we can send one to you.

An Oxfordshire charity, ‘Camerados’ says “the answer to all our problems is each other” and I have to say, I agree. From the teams of volunteers that run social groups, to the people who advertise them, donate raffle prizes, cakes and village halls, to the volunteer drivers who run shuttles to and from clubs, to the people who support the charities involved and of course, to the people who come along; wonderful things happen when we work together.

\* Carers Oxfordshire website (2016)

\*\* Carers UK Website (2017)

## From the Practice

We are sad to announce that Dr Boland has retired from the practice. He is sadly missed. Here are some lovely comments from a few of his patients.

"So sad to hear this, he has been amazing and so supportive to my family especially my husband. He will be missed by everyone but I hope he has a happy retirement with his family. He will be missed by so many."

"Absolutely fantastic Doctor, he will most definitely be missed. He's been fantastic with my parents."

"Such a lovely doctor and a lovely man. Was one of the best doctors ever in Witney."

"During my recent troubles he was awesome, always made time to settle my worries. First class human being and a man I admire greatly."

"Dr Boland is the best! He's so caring and always took the time to listen. On telling him that I was travelling to New Zealand he wrote me a 'prescription' of all the places he recommended I must visit. I still have that 'prescription' as part of my New Zealand memories. Top bloke!"

"Very sad to be losing the most wonderful doctor – nothing was ever too much trouble."

"His compassion, clinical excellence and self effacement put him in a superior class of his own. We will miss him tremendously."

"Such a kind and caring, old school doctor! If he is your doctor, you have every belief in what he says and I have always trusted his decisions. A real shame for him to go, but he totally deserves a great retirement!"



Tim Hughes

**I noticed that the practice is now called Witney General Practitioners Ltd. What does that mean?**

To most people, and to all our patients: absolutely nothing will change.

If you want to know the nitty gritty details, or are concerned about what this might mean, hopefully this document will be of interest.

As with all GP practices in the UK, ever since the introduction of the NHS the practice is run as a small business with a contract with the NHS to provide services to patients.

The vast majority of GP practices are, and always have been, set up as partnerships. A partnership is just one way of structuring a business. For GP practices, the partners are always GPs at the practice who directly provide the services patients receive. The GPs who are partners literally own and run the practice and are responsible to their patients and the NHS.

A limited company is just another way of structuring the practice (or any business). It will still be the same people delivering the same service in the same way.

**Is this just privatization? Is this a threat to the NHS?**

No. The practice is still providing NHS services, under the exact same contract that it always has done, that the majority of GP practices always have done (the "GMS contract"). Under this contract healthcare is, and always will be, free at the point of use.

**What about shareholders? Who are they and won't they want money from the NHS?**

The shareholders will be the same GPs who were partners under the previous structure. In fact under the current legislation and contract, it is only the GPs who could work at the practice who are allowed to hold these shares.

Previously some GPs took money out of the practice as self-employed individuals within a partnership. Now they will partly take money out as shareholders. It is exactly the same idea, just set up in a different way.

**Why was this done?**

We believe it the best option to have a sustainable GP practice for the future.

Ten or twenty years ago, practices would only consist of GPs in partnership and a small number of employed staff (such as receptionists and other administrative staff). Practices would also tend to be smaller organizations.

These days, a smaller number of doctors at a practice tend to be partners, and there may be various other clinical staff employed to see patients (such as our own paramedic practitioners or advanced nurse practitioners, or even other GPs as employees of the GPs who are partners). Practices also tend to be bigger. They may also have commercial contracts with other organizations (e.g. property or other services). Partners in a business of this kind take personal liability for all of this, including much of the clinical staff working under their responsibility.

To keep practices functioning as a partnership, it is essential to replace outgoing partners with new partners to keep the business viable and to take on the liability of running the practice. Historically the expectation was that mostly all GPs who complete training would join a practice as a partner eventually. A recent survey of GPs in training demonstrated that only 5% were considering applying for partnerships.

By setting the practice up as a limited company, we can attract young GPs without the need to ask them to take on the increasing risk that being a partner GP has over being a salaried GP.

**Are other practices doing this? If not, why not?**

It's actually not that common, but increasingly more practices are looking at this as an option. The process requires some investment of time and money for the GPs involved, which is probably the main reason that more practices haven't.

We are at the forefront of this, so it is very new territory. It will not in any way change or threaten the services the patients registered at this practice receive. All the changes will be behind the scenes.

## *Evidence 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.*

### **Preventing dementia: the evidence on vitamin and mineral supplements**

Despite the many important and positive inroads into our understanding of dementia in recent years, and a shift in emphasis from dementia being something people suffer from to something they can live with, dementia frightens us.

When it comes to dementia prevention, I think we may travel more in hope than expectation, but sometimes we can find evidence to see if our efforts might actually reduce our risk, and whether we could be doing ourselves any harm.

Two Cochrane Reviews have brought together the best available evidence on the safety and effectiveness of vitamin and mineral supplements for maintaining cognitive function and preventing dementia. In theory, these could help, as vitamins and minerals have many functions in our central nervous systems which may help keep the brain healthy and our minds working well. But is there robust evidence to inform our choices? Let's see.

#### **Vitamin and mineral supplements for cognitively healthy people**

##### **B vitamin supplements**

Taking B vitamin supplements probably has little or no effect on overall cognitive function at any time up to 5 years and may have no effect at 5–10 years. There are very few data on harms or on the incidence of cognitive impairment or dementia.

##### **Antioxidant vitamins: $\beta$ -carotene, vitamin C or vitamin E**

There may be some benefit in overall cognitive

function with long-term supplementation with  $\beta$ -carotene (after around 18 years of treatment) and with vitamin C (after 5–10 years), but an antioxidant vitamin combination or vitamin E, alone or with selenium, may have no effect.

##### **Selenium**

Selenium alone, taken for around 5 years, may have no effect on the incidence of dementia.

##### **Zinc and copper supplementation**

This probably has little or no effect on overall cognitive function, or the incidence of cognitive impairment, after 5–10 years.

##### **Complex supplements**

Combinations of B vitamins, antioxidant vitamins, and minerals may have little or no effect on cognitive function, after around 8.5 years of taking them.

##### **The review authors' bottom line is:**

“We did not find evidence that any vitamin or mineral supplementation strategy for cognitively healthy adults in mid or late life has a meaningful effect on cognitive decline or dementia, although the evidence does not permit definitive conclusions.”

##### **Vitamin and mineral supplements for people with mild cognitive impairment**

The evidence is very limited. Only B vitamins have been assessed in more than one trial. Taking B vitamins for 6 months to 2 years probably results in little or no difference in memory, thinking skills or quality of life, and the evidence doesn't tell us whether or not there are any harms.

##### **The review authors' bottom line is:**

“At the moment, it is not possible to identify any supplements which can reduce the risk of people with MCI developing dementia or which can effectively treat their symptoms.”

You can read the reviews in full at:

<https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD011905.pub2/full>  
<https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD011906.pub2/full>

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