Keeping Well?

The Newsletter of the Nuffield Patient Group

June 2014 Issue 5

Keep well whatever your age

In this edition of *Keeping Well?*, the focus is on keeping well whatever your age. Jan Burrage and her husband give an uplifting tale of managing life with positivity, even in the face of the tough reality of vascular dementia. Not all people with dementia are so lucky.

We also feature some background information on the scale of dementia in the UK, how to tackle memory loss as we get older and an update about the wonderful opportunities that we have in West Oxfordshire to keep well by regular exercise.

Sarah Chapman's article focuses on the evidence that exercise can be helpful if you have osteoarthritis, one of our commonest afflictions as we get older. Finally, PPG Vice-Chair Keith Shankland writes about the successful activities of your PPG during Patient Participation Awareness Week.

Living with vascular dementia

by Jan Burrage

When I was told that Ralph had vascular dementia, I was devastated.

A year before, mild cognitive dementia was diagnosed but to be told "dementia" seemed to be the worst I could imagine. I didn't sleep much that night but by morning I *knew* I had to learn all I could about dementia.

Help poured in by the bucketful – somebody came to help with this, another with that and soon my head was

swimming with information

but I still knew my one aim was to learn what dementia was, how it affected Ralph and how I was to cope with it.

I have eventually learnt that the awful things Ralph sometimes says is the dementia talking. I understand that, but still after three years I find it difficult to ignore.



Telling friends and family was hard but had to be done, and I always, even amongst strangers, when Ralph says or does strange things, I always say he has dementia and it's wonderful the way people respond.

We joined the Memory Café in Witney which was great for me. I met carers who had a lot more problems than I had. With the confidence we were gaining, we joined other groups. It's fun to be distracted for a while, learning new crafts and skills, and Ralph thoroughly enjoys the social side of things.

Continued from page 1

Ralph doesn't always remember what we do, but it always gives him a great feeling which memory loss can't take away.

Looking back, having had the courage to join these groups for dementia was the best thing ever. We have helped to make three films and a radio play, and with others we have toured museums and art galleries and attended a wonderful tea dance in Bourton organized by Val from the Memory Club of Chipping Norton and Carterton. So, instead of dementia being a millstone, it has become a source of energy and creativity.

Ralph's dementia will never improve and his memory is a lot worse, but he still retains a wonderful sense of humour. His love of music and art is a great comfort to him and he regularly plays in Oxford with Gemma who is a music therapist with Guideposts. He also did a brilliant guitar solo on BBC South. He attends the Elms twice a week, which he thoroughly enjoys and of course it gives me a few hours to relax.

Dementia does destroy active lives but there's always hope that some time a cure can be there for the future.

And as for me, I'll never really understand the complexities of dementia and I still have a lot to learn from the many friends we have met over the past few years. To them especially I say a big thank you.

Alzheimer's disease: a fact file

from the Alzheimer's Society

The UK has 800,000 people with dementia.

Research shows that dementia is the most feared condition of people aged over 55.

A diagnosis of dementia is not an end to quality of life.

Medications can help slow down the progression of symptoms for a time.

No two people will experience dementia in the same way.

We all have a role to play in ensuring that people with dementia can live well.

People should have need when they need it.



Support can be given by carers at home and services run by organizations such as the Alzheimer's Society.

At the heart of Alzheimer's Society's Dementia Friendly Communities programme is raising awareness among the general public to reduce stigma and make communities more inclusive and supportive of people with dementia.

An archaeologist is the best husband a woman can have. The older she gets the more interested he is in her. *Agatha Christie*

Tím Hughes

Worried about your memory?



Should I be concerned about my memory?

It happens to all of us at some point. You can't put a name to a face. You forget where you put your car keys. You can't remember where you parked the car. Most of the time, such slips are a nuisance, rather than a sign of something more serious.

The earlier you seek help, the better, as there may be support or treatment available that can help you

But if you are worried that your memory is getting noticeably worse, or if memory loss is beginning to affect your everyday life, it is worth seeking advice. You might also be concerned about someone close to you. It's important to seek advice because, in some cases, memory problems are an early sign of a medical condition such as dementia.



What should I do if I am worried?

If you are worried about your memory, talk to your GP. They will listen to your concerns and possibly arrange for further investigation. You may be referred to a local memory clinic or hospital for further investigation where a formal diagnosis can be made.



If you are concerned about the memory of someone close to you, encourage them to visit their GP. You might start the conversation by gently asking the person if they've been feeling any different from usual or are struggling with anything.



It's important to know that there are many reasons for memory loss apart from dementia. These can include depression, infections and vitamin and thyroid deficiencies.

For more information, you can phone:

- Alzheimer's Society's National Dementia Helpline on 0300 222 1122
- Susan Smith, the Alzheimer's Society's dementia support worker for West Oxfordshire on 07833 952 514

Maintain cognitive function with physical activity

by Bill Wragge, Health Policy Officer at West Oxfordshire District Council

The benefits of physical activity include maintaining cognitive function as well as improved self-esteem and reduced risks of cardiovascular events and falls.



Sport England statistics show that only 20% of those aged 65 or older participate in sport or active recreation once a week in West Oxfordshire. Leading a sedentary lifestyle can be detrimental to health and wellbeing, with increasing effect with age.

Fit and healthy adults aged 65 or older should aim to be active on a daily basis. This should consist of moderate-intensity aerobic exercise, such as fast walking, water aerobics or riding a bike, and muscle-strengthening activities that target all the major muscle groups, such as yoga.





Across West Oxfordshire, we have three leisure centres and one sports centre, owned by West Oxfordshire District Council and managed by Better. The centres offer a range of opportunities that cater to the needs of older people, such as circuits, yoga, swim sessions, chair-based exercise, pilates and general gym.

Margaret Jones, aged 65 years, uses the Windrush Leisure Centre. She started an exercise referral programme in January 2014. She hadn't participated in any exercise for over 2 years and had a knee replacement in April 2013. Following her initial assessment, Margaret was given a low-impact, low-intensity gym programme incorporating aerobic and strengthening exercises. After 12 weeks, Margaret's cardiovascular fitness and strength had increased enough for her to graduate as an independent exerciser. Now, she is doing 75 minutes of moderate-intensity plus 30 minutes of light-intensity aerobic exercise per week.

Originally, Margaret scored her overall health as 40/100; now she rates her health as 70/100 – an amazing result!

For more information about independent exercising, contact your local centre:

Bartholomew Sports Centre (Eynsham) 01865 731090

Carterton Leisure Centre 01993 840933

Chipping Norton Leisure Centre 01608 644412

Windrush Leisure Centre (Witney) 01993 202020

Patient Participation Group -Awareness Week

by Keith Shankland

Monday 2nd June saw the start of National Patient Participation Week where many patient groups across England, including the Patient Participation Group at the Nuffield Practice, led a campaign to increase awareness of the role of patient groups and how they support doctors and practice staff to develop and evolve patient services at a local level.

Our patient group aims to support patients and the practice in many ways, including giving feedback on patients' needs, concerns and interests, providing suggestions to influence service improvements and assisting the practice in promoting good health.

Dr Phil Hammond, GP-turned-hospital-doctor, journalist and broadcaster, supported the national awareness week, saying:

Patients and carers are the smoke alarms for the frontline of the NHS. They are often first to spot poor care and also have great ideas about how to make care better. They need to be involved in decisions not just about care, but in designing better care for others. Patient Participation Groups are a crucial way of harnessing the voice of the patient in primary care, and have much to contribute in driving up quality.

Our theme for the week focused on the importance of patient self management and wellbeing by promoting such things as healthy eating, smoking cessation and "looking after your heart" – all good examples of aspects of health that can be successfully managed by the individual patient, doctor and other healthcare professionals working together.

Throughout the week, we had a stand in the reception area manned by members of the group which gave us a great opportunity to speak to patients about these important issues and provide supporting information and leaflets.

Speaking to patients also gave us an opportunity to explain the activities of the group in more detail and how we represent patient views and needs with the practice staff. We received a number of positive comments about the environment within the surgery and the helpfulness and professionalism of the staff, together with a number of suggestions for service improvements. We will be discussing these with the practice team at our next meeting, in July.

Our patient group is a crucial way of harnessing your voice

Finally, the patient group exists to represent your views. We are actively seeking new members to join us to ensure that we have a representative cross-section of the patient population. It is not a large commitment – we meet with the practice team four times per year.

If you would like to join us, please contact Catherine Simonini, Practice Manager (<u>Catherine.simonini@nhs.net</u>), Graham Shelton (<u>graham.shelton@pharmagenesis.com</u>) or Keith Shankland (<u>keith.shankland@ntlworld.com</u>).

Alternatively, you can use the "Have Your Say" leaflets to feedback your comments, needs and suggestions (anonymously if you wish) and we will take these up on your behalf. These leaflets are available in the reception area along with a "posting box".

Patients and carers are the smoke alarms for the frontline of the NHS

Our sincere thanks to all the staff at the practice who supported us throughout the week, especially our colleagues on reception.

Evídence Matters

by Sarah Chapman

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

Do you have osteoarthritis? Exercise can help!

We're always being told that exercise is A Good Thing, aren't we? Whenever I write about research on exercise and health, I always hear from lots of people that, whatever the evidence, exercise makes them feel good – and that's a great reason to do it!

How about if you're someone with osteoarthritis (OA), which makes joints such as the hips and knees feel stiff and painful?

Let's take a look at the evidence. There's good news!

• We have really good evidence that land-based exercise, such as muscle-strengthening exercise or aerobic fitness programmes, can reduce pain and improve hip function in people with hip OA.

• There's also really good evidence that a regular, supervised exercise programme can reduce pain and improve knee function in people with knee OA. The effects are small but thought to be similar to improvements seen with non-steroidal anti-inflammatory medicines.

• We don't know which types of exercise work best or whether it makes a difference if people are supervised in groups or individually. This evidence shows that exercise can help reduce symptoms of OA; we don't know if it has any effect on how the disease progresses.

There isn't much evidence about water-based exercise for OA but what there is suggests there may be some benefit for people with hip and/or knee OA.



Why not ask your physiotherapist, nurse or doctor about exercise and see if it helps you and your joints as well as giving the benefits that exercise offers all of us. That would be good news!

You can see the reviews in full at www.thecochranelibrary.com

Bartels EM, et al. Aquatic exercise for the treatment of knee and hip osteoarthritis. Cochrane Database of Systematic Reviews 2007, Issue 4. Art. No.: CD005523.

Fransen M, McConnell S. Exercise for osteoarthritis of the knee. Cochrane Database of Systematic Reviews 2008, Issue 4. Art. No.: CD004376.

Fransen M, et al. Exercise for osteoarthritis of the hip. Cochrane Database of Systematic Reviews 2014, Issue 4. Art. No.: CD007912.

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