Notes from the Elmswood Surgery Patient Group Meeting Wednesday June 13th 2018

Present: Derek Huett, Shelagh Clarke, Magrit Mitchell, John Hackett, Dave Groom, Pauline Sault, Irfan Malik, Suzanna van Schaick, Charlie Wilson, Edward Skardowa.

Apologies: Amanda Roberts, Sue Wilson, Mary Spencer, Adele Horobin

We had a visit from Trevor Clower who came to talk about the role of carers, the Carers' Roadshows and what can be done in the event of the death of a carer.

Trevor talked about his experience as a long term carer and about how carers can feel very isolated not knowing that there are people with similar experiences to share. He attends many meetings at all levels of the NHS and promotes Cares' Roadshows as a way of bringing together organisations whose focus is on supporting carers in one place — a sort of one-stop shop. As with all these events it is hard to raise awareness with carers that the Roadshows exist as a way getting carers the support they need.

He spoke about long term and instant carers. The latter being those suddenly thrust into the role and often not equipped with the skills to take on the role long term.

Trevor explained to us how he sees the five impacts on long term carers:

- 1. Effects on the normal job with 24/7 having to be there.
- 2. Your social life evaporates.
- 3. Family support often drifts away.
- 4. Often feelings of being on your own with the patient. A good example is that professionals in the NHS tell the carer what to do or ignore their input.
- 5. The carer can often wind up in A&E because they have become ill or exhausted by trying to cope on their own.

Trevor talked about the triangle of care between the patient, the carer and the and how managing this professionals to come up with an effective care plan for the patient can be fraught with issues of balance of input. Involving the carer needs to be seen as a crucial source of information about the patient because it is likely that the carer knew the patient before they got sick.

As to the Roadshows, Trevor organises stalls at different venues – he distributed a current list, a copy which is now on the notice board in the meeting room. What works well is that carers can sign up immediately with stall holders and get advice and support with which they feel supported and able to cope better. The Roadshows connect carerswityhn options to support them. Trevor vets organisations which want to take stalls. The Roadshows are organised where it's been found that there are lots of people around – eg Health Centres, town markets and hospitals foyers. In the last 10 years 11,700 carers have had 1:1 support from Roadshows.

Trevor then spoke a bit about what happens when a carer dies.

Carers often don't make provision for when they are no longer there. In the event, the patient becomes the responsibility of the local authority with a duty of care. The process is then to put that patient in a care home where they are disorientated away from what is familiar to them. The patient's behaviour may alter radically and despite the best efforts of care homes, these patients become labelled as angry, sometimes violent and disruptive. Nobody in the new provision has

experience of the patient before they became ill or what they were like in their own surroundings. Also when a patient is realised from hospital it is vital that the carer's details included in the discharge process.

At the same time carers sometimes have to let go a little before they over extend themselves and get a care package sorted out for themselves and involve the patient's family to a greater extent. Although it seems a bit down beat, Trevor urged us to think more about death and its implications for all concerned.

There was a suggestion that for the 2019 Sherwood Art Week, Trevor might be able to organise a Roadshow in Sherwood. As it is reckoned that about 75% of the population knows someone who is a carer, or knows a carer or is a patient, this might help raise local awareness and offer support locally to carers.

Our next meetings:

- Friday 13th July 2018 2pm Ian Trimble Ian Trimble, ex of this organisation. Will talk about his current role within the NHS
- Wednesday 12th September 2018 6.30pm Deena El Shirbiny talking about Social Prescribing
- Friday 12th October 2018 2pm Sally Bell will be talking to us about lifestyle medicine
- Wednesday 14th November 2018 6.30pm Dementia Friends with Mark Towlson
- Friday 14th December 2018 2pm

Hope to see you at any of our meetings which all take place in the meeting room upstairs at Elmswood Surgery. Please expect the meeting to be an hour and a half. Please note that the surgery **closes at 6.30pm**, so you need to arrive a few minutes before the start time of the evening sessions.

Our surgery's news

Latest results from the government's "friends and family" test for our surgery are from May of this year when 10 respondents gave positive feedback for our surgery. You can give **your views** about the practice in this very short questionnaire Some questionnaires will be available in reception for you to fill in and return. Alternatively you may do the questionnaire online at www.cfep.net/0qt

Welcome to locum doctor Deena El Shirbiny.

In the news

The 2018 Nottingham and Nottinghamshire Carers Road Shows

This year is the sixth year of the Summer Road Shows for carers. Each year they are bigger and better with more and more people visiting. The shows were started by and are still organised by Trevor Clower, who is an unpaid carer. The Carers Road Show offers free support for all unpaid carers, no matter what the circumstances of the person they are caring for. The unpaid carer can sign up for the support they qualify for there and then at the stall. Alternatively the carer can simply browse and take away information. Pop along to one or more of the shows and see for yourself the range of help and support there is available.

Venues in our area:

Friday 13th July Valley Health Centre, St Ann's

Wednesday 1st August Southglade Park Life Festival, Top Valley

Tuesday 14th August Mary Potters Health Centre, Hyson Green

Friday 7th September Riverside Health Centre, Bulwell

Health commissioners from the four Greater Nottingham Clinical Commissioning Groups are consulting on whether the local NHS should restrict or stop gluten free food on prescription. The six-week consultation will run from **Thursday 14 June to Thursday 26 July** and they are asking people to complete a short survey to help them to understand what people think about the different options.

How to have your say

- Go to: www.surveymonkey.com/r/GN-gluten-free
- · Call: **0115 883 9594** (City patients) or **0115 883 1709** (County patients) for a printed copy or to complete over the phone

For more information...

· Read the consultation document here.

Important information regarding your personal data

The new EU-wide General Data Protection Regulation (GDPR) comes into place on 25th May 2018 and will replace the Data Protection Act. As a member of the Elmswood Surgery Patient Group we keep a record of your name and contact details. This information is held on a password protected database on Mailchimp, accessed only by the secretary of Elmswood Surgery Patient Group (currently Amanda Roberts). Your data is not shared with any other organisations/ institutions. The Elmswood Surgery Patient Group will use your email address to communicate with you generally twice monthly (to notify you of the forthcoming meeting arrangements and subsequently what happened in that meeting). With those mailings will be details of other health and social news we hope might be of interest. We may very occasionally contact you at other times when we are seeking your assistance. If you wish to unsubscribe from these emails, and therefore cancel your membership with us, then you can do so at any time: click "unsubscribe" at the bottom of this email.

You are welcome to contact us if you have any questions about this.