



Shropshire & Mid Wales
Cancer Forum

Notes of Meeting 14th July 2015

Attendance: Sian, Colin, Rachel Redgrave, Julia McAdam, David Whiting, Kim (Get fit advisor), Bernard, Sue, Becky Willetts (Brain tumour group)

Apologies: Rob, Vicky (Macmillan), Roger, Irene Constable (BOTS support group)

As a patient with Cancer, did you know- it was agreed to have this actioned as soon as possible and to evaluate at a later date, approximately 3 months possibly by forum members sitting in reception asking people if they had received it and if it was useful. The appointment letters are printed externally and only in black and white, there is no option to have them printed in colour.

Posters also to be printed.

Action: Sian to liase with Rachel /Julia
Sian to arrange printing/laminating posters
Julia to advise quantity & size

Ask3 questions poster, final version needs 'tidying up' prior to printing.

Action: Sian to liase with Rachel /Julia

Opening of Telford macmillan Information centre

The forum received an invitation to the official opening on 17th August, where we can have a stand. Our leaflets will be put up at the centre.

Jessica Brindley is the new information manager and will spend two days at Telford, Julia will invite her to our September meeting.

Two days a week the benefits service will be at the centre and one day Kim , Get Active, Feel Good advisor will be at the centre.

Action: sian to let other forum patient representatives know, arrange stand & leaflets for the Telford centre

Follow up appointments, Breast & Prostate

This is progressing well and has now gained executive support. The next step is working with the local IT department and investigating costings.

Survivorship

HOPE programme details have been sent to the therapy team, anyone interested advised to contact macmillan directly

Treatment Summary record. Julia advised that colorectal team produce something, the oncologists just send copies of all letters to the patients and everywhere else is very ad hoc. The person to contact to pursue this would be Angie Cooper

Action: Sian to contact Angie.

Lung Cancer Support Programme

This is going to be a 4 week programme of information & education, mainly delivered by the Macmillan Therapy team..

Week 1.

Hamar Centre introduction and what they can offer.

Eg counsellors, complimentary therapies etc.

Mention of PEIP and the Forum.

General signposting.

Week 2.

Macmillan to do a session on benefits, entitlements etc.

Activity - Get Good Feel Good etc.

Week 3.

Fatigue and breathlessness.

This will be patient led but will cover feelings of anxiety and techniques to help overcome those feelings .

Week 4.

Speech and language therapies.

Explanation of side effects and what to do to help with those.

The programme starts on 9th September and patients can start on any week. There are 12 places available each week. Evaluations will start after the first 4 weeks, for patients completing all 4 weeks.

National Cancer Patient Experience Survey

St Georges are visiting the hospital for a full two days. The forum has been invited to send a representative next Wednesday. The formal partnership with St Georges ends December. The partnership is being formally evaluated.

As part of this initiative SaTH have worked with macmillan to get some staff trained on 'sage and time' which will enable these staff members to train non clinical staff on how to talk to patients. There over 600 staff and it is hoped to train them all over the next two years. The forum welcomed this initiative.

Update –Kim . , Get Active, Feel Good advisor- there was a steering group meeting yesterday. Funding has been approved for the 4th year. This is a collaboration between Macmillan and Sport England and Shropshire Public Health. SaTH is one of 6 beacon sites, out of 80 running activity schemes in England. To date there have been 402 referrals into the program. Kim's hours have been extended.

Update – Becky. They are currently reviewing all of their services. Becky reported that the new Rarer cancer nurse CNS (Di), is excellent and making a real difference to patients. They are running an event for people with brain tumours on 22nd September.

Update – David the new NICE guidelines for 2 week wait cancer referrals are now published and live. The Trust has to write new pathways. Some of the guidelines are useful and clear, some less so.

Update – Julia Patient Charter, this had previously been circulated to patient, carer forum members for comments. It has been well received by the PIEP and now has to go through formal approval of several departments. It is hoped to launch in August/ September

Update – Bernard reported that many cancer patients and others with long term illnesses have reported excellent rates of insurance with <http://www.insurancewith.com/> Bernard gave an example of one person having received other quotes of £1800 having a quote of only £200

Action: sian to add to website & advise Hamar Centre

AOB

Julia gave her apologies for the September meeting

NEXT MEETING: TUESDAY 8th September, 2:30, HAMAR CENTRE, ROYAL SHREWSBURY HOSPITAL, SHREWSBURY