



Shropshire & Mid Wales
Cancer Forum

Notes of Meeting 14th February 2017

Attendance: Sian, Colin, Clare, Irene, Jan, Pete, Jean Garner (Macmillan), Angie Cooper (Matron for Oncology and haematology)

Apologies: Sally Hodson, Roger Rob, Vicky, Richard, Sue,

Radiographer video – Louise Killey from radiography came over to share with the group their DVD's for patients. They have one for breast, one for prostate and one for head & neck patients. The group watched some of the head and neck and the following suggestions were made: subtitles for the hard of hearing, information on how to access help when staff have left the radiography room, divide the DVD's into sections so people can easily access the bits that they are interested in, this would give people the option of skipping any bits they are comfortable with (eg getting weighed and consented which should otherwise be omitted as everyone is familiar with consent by the time they reach a radiographer) and concentrating/repeating on unknown areas, a section for carers with for example where to wait, how long it will take, things to look out for.

Louise agreed to bring the DVD's over again next month at 2 o'clock so we can watch another before the formal meeting starts. We were surprised by the length.

Dates of future meetings to be emailed to Louise.

Action Sian

Website – Sian confirmed meeting dates have been amended on the forums website.

Statistics/ information for chemotherapy patients– Sian spoke with CRUK and they have advised they use information in addition to that available to the manufacturers of the drug. This includes accessing an Electronic Medicines compendium and trials data that is not in the public domain. They believe therefore that their information is more accurate than that included with the packaging.

Their leaflets are normally reviewed and updated once a year, however, as they are in the process of transferring all the drug information to another website, they are currently behind this target.

Regarding the discussion of survival data referring to simply being alive in x years or being alive and disease free in x years. The explanation I was given was, there are many areas of statistical data which can use different definitions, generally it is simply alive in x years. However, if the data is from trials it will be someone is disease or event free in x years.

There was much discussion on patients being given the right information for them to make an informed decision on treatment options. It was agreed everyone was different and some would choose for example to have chemo even if it only improved their survival by 1%, while others would want more detailed information. Macmillan are the standard leaflets provided by the hospital. We asked if the hospital would consider giving patients the option of CRUK information. Angie is going to investigate for us, a minimum would be to recommend the CRUK website.

Angie explained that both breast and urology have specific databases where they can input all the patient information to get statistics, Angie will see what the other tumour sites have to see how they arrive at the statistics they are giving patients.

Action Angie

Pre Treatment chemotherapy information session- An audit started last week which will last one month, they are going to find out how many people invited, how many people didn't attend and why, how many people having the information session on the same day as chemo. In the first week, one chose not to attend as the date wasn't convenient and the other was due to clinical need ie chemo needed to start urgently.

Everyone agreed patients need to take responsibility and should be attending (unless clinical reasons for urgent chemotherapy), but this needs to be communicated to patients.

We also discussed how patients would know they need a thermometer, and that having indigestions and constipation drugs in the house is recommended if they don't attend the pre chemo information session. Colin suggested we see if the League of Friends shop could stock these items, so people could be directed there, rather than have to endure a trip to the shops after receiving their first round of chemo, when they are unlikely to be feeling well enough to go shopping. Angie agreed to contact the League of Friends.

Action Angie

Chemotherapy alert cards –Angie advised that from April these cards will be pre printed to include a pre-prescribed dose of antibiotics on the card. This means if the patient goes to AMU or EMU, they will be able to get the pre prescribed antibiotics without waiting for a Doctor, this will speed the door to need time. The patient will still get properly examined and treated, this will simply speed up the first dose of antibiotics which is critical to patient safety.

Cancer Wellbeing event-Clare visited origins, the Sixth form college, still waiting on a response to email requesting costings.

Jan Contacted the central church in Shrewsbury, who have an excellent room upstairs. It would cost £120 + £20 for the kitchen.

Irene suggested we can get platters of sandwiches from Costco for £8 per platter. Irene would be happy to arrange for us.

Jan is going to check availability for Mondays and Wednesdays (non market days) in September.

We discussed speakers and what would attract people to the event, healthy eating was a positive suggestion, with ideas of a number of short talks with different titles, covering for example general healthy eating, food to tempt the pallet on chemo.

We thought that with healthy eating, inviting Kim to talk and possibly lead a seated activity session would fit in well, to make a healthy lifestyle.

Angie agreed to speak with dieticians to see if they would be interested in getting involved.

Macmillan were approached for funding and have requested more information. Sian will follow up Macmillan.

Action Angie

Action Sian

Lymphoedema – Sian and Clare have met with both the hospice and Telford & Wrekin CCG. The hospice have been funding the service themselves as they have received insufficient

funding from the hospital to cover the service they were providing. They accept referrals from both the hospital (cancer patients) and the community usually non cancer patients. The hospice advised they wrote to all patients without a hospice appointment to let them know of the changes. They are currently only providing the service from the Shrewsbury site, due to funding and as they believed it to be more efficient. We have sent details of voluntary transport services available in Shropshire which the hospital agreed to share with patients. They also advised that there was (at the time of the meeting) there was no waiting list for referrals to get back into the service. They also had a meeting arranged with the commissioners to try and find an easy and efficient way for GP's to find the correct prescription garment on EMIS.

T&W CCG meeting confirmed they are still working with the hospice to contract a service for Telford patients (the contract would be a joint one with Shrewsbury CCG), they expected Telford patients to be treated at the Telford hospice. They were also very keen to find an efficient way for patients to get the correct prescription and were looking at various options for this. They agreed to keep us informed.

Action Sian

Hospital food – Sian, Clare & Irene met with Helen Coleman. Helen advised there was one housekeeper per ward and one health care assistant per bay. Housekeepers don't work weekends or evenings. It is usually the HCA's role to give out and collect menus. Helen hadn't seen ALL the menus that catering had shared with us. Helen agreed to contact the colorectal ward manager to review the failings of care for our unnamed patient. Discuss with the appropriate training person awareness of the different menus and raising this with staff

Prepare a one minute briefing to go out to all staff to reinforce the message that ringing the kitchen is an option

Will look at adding Dairy Free as an indicator on the menus

Helen has asked we encourage patients and carers to feedback whilst on the ward any problems, alternatively to use PALS. And to share with Helen any further food issues we become aware of.

Anyone to email Helen with any patient stories. Sian to share Helens email address

Action Sian

Stoma friendly toilets- Irene advised the group that for a disabled toilet to be stoma friendly it needs a hook, a small shelf and a disposal bin. The group was shocked to find that the toilets on ward 25 are not stoma friendly, yet this is where stoma patients are. Angie agreed to take this back to the hospital and see if disabled toilets can become stoma friendly, starting with ward 25.

All the group were given an information sheet and it was suggested that they could ask when they encountered disabled toilets. Irene and Sian have a number of stoma friendly stickers which we can put on disabled toilets that meet the requirements. Irene is compiling a list of friendly toilets, so if anyone finds one or has one improved to meet standards, please let Irene know.

Action Sian

Prostate cancer deferred to next meeting. It is an agenda item to discuss the best diagnostics available to patients, the effects on patients when these aren't used and if appropriate the options going forward with this item.

NEXT MEETING: TUESDAY 11th April 2017 HAMAR CENTRE, ROYAL SHREWSBURY HOSPITAL, SHREWSBURY