

Sarcoma South UK Support Group

Minutes of Sarcoma Support Group Held on Wednesday 12th March 2014

at Sunrise of Bassett, 111 Burgess Rd, Southampton SO16 7AG

Present:-

SM1, SM2, SB, DH, TM, SH, EC, MM, RM, YP, TP, LC.

1. Apologies/Introductions

Apologies were received from RK, IM, SS.

New member LC was welcomed by the group and she shared her experience of being diagnosed with synovial sarcoma and being treated with radiotherapy, chemotherapy and surgery last year. Members introduced themselves and gave an update on their sarcoma treatment/surveillance. Issues discussed included delay to diagnosis, side effects of radiotherapy and treatments, taking early retirement, the importance of holidays and anxieties associated with fear of recurrences and trying to protect carers from the worries.

1.1 DH said that Wessex Cancer Trust has a new facility in Southampton.

1.2 Several members of the group (MM, DH, TM) have joined local Patient Liaison Groups at their GP surgeries. Two are virtual groups, but MM's group meets face to face and is very successful. Members of that group leaflet patients attending the surgery, which has public evening sessions devoted to special topics. TM mentioned that Macmillan was urging cancer patients to join their local group, especially to ensure that cancer patients receive proper services. All GP surgeries are supposed to have a Patient Liaison Group, for which they receive special funding.

2. Minutes of the last meeting were taken as read.

3. TM attended the British Sarcoma Group 3-day conference in Nottingham. She felt it was the best one she attended. Because we were running out of time, T said she would prepare a summary of the conference and email it to group members. We will then discuss it at a future meeting. T is going to attend the Sarcoma Voices meeting in Birmingham later this month. It is sponsored by Sarcoma UK and will focus on sarcoma support groups.

4. There was a discussion of the reorganisation of the NHS in terms of reducing the number of hospitals and creating centres of excellence. While this had advantages, it is often difficult and impractical for unwell cancer patients to travel far.

5. Treasurer's report: The group has enough funding for the time being. We will be printing new leaflets and obtaining laminated posters. TM and DH will work on the posters. We will apply for funding from Macmillan later this year. SB will bring details about the grant application to the next meeting for discussion.

6. AOB:

- SM1 suggested that we put a notice in the Echo announcing our meetings. This is available without cost as it is a news item. TM will look into this.
- A group of patients from the Independent Cancer Patient Voices had sent out a questionnaire about cancer patient experiences and opinions of follow-up. SM2 was concerned by the possibility of cancer patients being followed up by GPs which would be a bad idea for sarcoma patients. He wrote to RW, who sent a long reply, agreeing with SM2, and Sarcoma UK are involved with discussions with the sarcoma clinicians about the issue of follow up. TM said that Macmillan have been working on the issue of follow-up care and Macmillan recommend that rarer cancers such as sarcoma would continue to have follow-up care with specialist teams rather than GPs. The London and South East Sarcoma Network's Sarcoma Advisory Group which include clinicians from UCH, RMH and RNOH are working on specific follow-up guidelines for the various subtypes of sarcoma.

Next meeting:

**14th May 2014, 2 to 4 pm at The Grove Hotel, 2 Grove Road, Bournemouth BH1 3AU,
01202 552233**

(TM 12/04/14)