

Sarcoma South UK Support Group

Minutes of support group meeting held at The Grove Hotel, 2 Grove Road Bournemouth on Wednesday 9th September 2015 at 2pm

Present: TM; SM1; SM2; SB; LB; TS; PB

1. Apologies: RK; LC; SH; MG; JB; CG1; CG2.

2. Minutes 8th July 2015 taken as correct.

3. Guest Speakers: Tracy Street Macmillan Involvement Coordinator and **Paula Bond**, Macmillan Development Manager were welcomed to the group. They have been instrumental in the initial setting up and help with sustaining the group. They outlined how Macmillan is supporting cancer services in Dorset. The focus is on providing funding for developing new services where gaps exist. 60-70 Macmillan professionals are in post, some are funded (“pump primed” funding for 3 years with the expectation that the NHS will pick up the service and continue) and others are given support by them having access to Macmillan training and education and support. There is a mixture of dieticians, physios, welfare Benefits Advisers, GPs and Clinical Nurse Specialists (CNS).

Three Macmillan GPs are employed 1 or 2 sessions a week and their main role is to influence GPs and monthly sessions are run for GPs to help raise awareness of and education about cancer. “Macmillan Minute” is a new initiative in which GPs have access to 5 Power Point Slides on set topics, usually the more common types of cancer and only take a minute to read. Another initiative has been sessions for GPs starting at 3 pm and finishing at 8pm including supper. These feature a “speed dating” style of learning whereby each table features oncologists specialising in the more common cancer types and doctors move to each table. The group offered to help raise awareness of sarcoma and would like sarcoma to be added to the education programme.

There are to be 3 new Macmillan Acute Oncology CNS working in Accident and Emergency Departments in RBH, PGH and DCH – the latter is already in post.

Macmillan are funding a physical activity programme “Dorset Living Well Active” <http://www.livingwellactive.org> contact Layne Hamerston: email: laynehamerston@live.co.uk and Tracy is sure he would be happy to either attend the support group or send some information about the service.

Macmillan has funded a full time post for a Clinical Psychologist who started this week.

Dorset Macmillan Advocacy - <http://dorsetmacmillanadvocacy.org> one-to-one support, help, and advocacy for people over 50 affected by cancer. They are based in Help and Care office in Pokesdown and in Poundbury.

Macmillan mobile Information Unit successfully visited the recent Steam Fair. Information and Support Project Manager Jane Simkin was recently appointed in Dorset and the group offered their help to Jane. Macmillan are going to fund "Information Pharmacists" at Boots.

In 2014/15 £1million was spent in Dorset. New projects have included "Rising Voices" choirs; "Afterglow" radiotherapy support group; "The Living Tree" in Bridport; "Fire Dancing" belly dancing and a planned yoga group for women with secondary breast cancer. Tracy thinks we may be able to apply for another Macmillan Grant and she also has information on companies that make small donations that may be able to help us in the future. **(NB Tracy has sent us Macmillan's "Supporting You to Help Others Guidelines.")**

4. **Macmillan End of Grant Report:** SB and TM have been working on the draft and it is nearing completion. Sarcoma UK did not wish to facilitate a float for our expenses, Sue is going to contact them and clarify procedure for claiming expenses.
5. **Purbeck Workshop** www.purbeckworkshop.org a workshop in Wool, Dorset set up and running arts and handicraft classes for people affected by cancer. Tracy says they would be happy to come and talk to our support group.
6. **AOB**
 - **RNOH Stanmore are conducting a patient experience project and Steve and Tricia are participating. Initial discussions highlight praise for the staff and criticisms about outpatient appointment system.**
 - **RMH clerical system seems chaotic, many mistakes around patient letters. CNS to be informed. PALS may need to be involved.**
 - **Lindsey Bennister CEO Sarcoma UK is going to a round table discussion at the European Bone Sarcoma Network about research and she is speaking to patients about their views before she goes.**
 - **Macmillan Cancer Voices Conference have asked TM to take part in a workshop on setting up and running a support group.**

7. Date for next meeting: Wednesday 11th November 2015, 2 – 4pm, The Grove hotel Bournemouth, 2 Grove Rd, Bournemouth BH 1 3AU (01202 552233)

2016 dates for Bournemouth group: January 13th; March 9th; May 11th; July 13th; September 14th; November 9th - all 2 -4 pm at The Grove hotel.

(TM 10/9/2015)