

MINUTES OF JOINT PATIENT GROUP MEETING

HELD ON WEDNESDAY 13 JUNE 2018

Present: Debra Warren (Community Matron), Jodie Wharton (Community Nursing Sister), Jane Carr (Macmillan End of Life Educator), Alison Hembrow (Treetops Hospice), Emma Plummer (Place Lead AV)

John Flinders (Park Chair), Margaret Flinders (Brooklyn), Paul Mason (Kelvingrove), Rosita Dowdall (Park), Pauline Briggs (Park), Mary Shaw (Park), Leslie Foster (Park), Anne Tompkinson (Park), Mandy Hallam (Park), Jane Wharton (Park).

INTRODUCTIONS – were made.

APOLOGIES – received from Barry Wood, Viv Palfreyman, Lesley Hall.

MINUTES OF LAST MEETING – were agreed as a true and accurate record.

SPEAKERS – Debra Warren (Community Matron), Jodie Wharton (Community Nursing Sister)

Debra and Jodie made a presentation to the group entitled 'Dying Matters, What Matters to you Matters to us'.

They each explained their role, discussed some of the myths around end of life care and the importance of person centred end of life care.

They asked the group what they feel is important in end of life care. The comments included; lack of pain, peaceful death, being involved and conversations not happening without their knowledge, how to manage day to day running of house if they live alone, etc.

Debra and Jodie acknowledged all of the concerns and expressed the need to make staff aware of their wishes as early as possible. It is important that health professionals know what is important to a patient to enable the right care at the right time and in the right place. They then have to communicate and share that information appropriately. The aim is for a good quality of life until the end wherever the patient wants. Patients should not assume that they will not be able to die at home even with complex needs as this is not the case.

All acknowledged the difficulties in raising the subject and this has to be done once a relationship with the patient has been developed. The intention is that the patient and family have the best experience possible of end of life care. Knowing that the patient's wishes have been met is a great comfort to all involved.

Members shared their experiences of end of life care. Some members had bad experiences of the Liverpool Care Pathway which prompted health professionals to stop patients having any food and drink towards the end of life.

Debra and Jodie acknowledged their concerns, but stressed that any document should follow the patient and not the patient follow the document. Patients are encouraged to eat what they fancy when they fancy with the aim for the best quality of life until the end.

Anne reiterated that the Liverpool Care Pathway was a tool used to acknowledge that someone was dying so that things could be put into place, but communication is fundamental whatever tool is used. She stressed that the pathway is no longer used.

All agreed that person centred care is most important and that discussion around end of life as early as possible is appropriate. If left too long and a patient loses capacity health professionals cannot respect their wishes and decisions have to be made on their behalf.

Debra showed a brief overview of the RESPECT form that will shortly be used to collect and communicate relevant information around end of life care. She reiterated that community teams will work together to provide a wraparound service supporting the person and their family/care to fulfil their wishes.

QUESTIONS

John asked how patients can access MacMillan services. Jane Carr explained that she is not directly involved in Macmillan, but that her role is as an educator attending GP practice and nursing homes to talk about end of life care.

Anne asked Alison to give an overview of counselling services provided by Treetops Hospice. She explained that there is a range of services including practical support to give an overview of services available, how to access, etc as well as trained counsellors to provide psychological support to people living or dying with a condition, counselling for family members, bereavement support and counselling for all ages. Over 18s can refer themselves by phone. Under 18s can be referred by a GP, school, their parent, etc.

Emma informed members of the Dying Matters website which has a lot of useful information.

DO WE WANT ANOTHER JOINT MEETING

Yes agreed to have another joint meeting. Please let John know of any ideas for speakers.

ANY OTHER BUSINESS

None.

CLOSE OF MEETING

The meeting closed at 8 pm.