Case study

Supporting patients to make decisions about their care at the end of life

Patient Notes

- Sally Jackson – 49 years old, lives in supported accommodation, diagnosis of Downs Syndrome
- 12 month history of Breast Cancer – been receiving chemotherapy with side effects. She has been accepting treatment as she believes it will cure her.
- Recent investigations show Cancer has spread and now is terminal

Dr Michaels (oncology SpR) is seeing Sally with her support work Kim in outpatients

Dr Michaels explains the recent results, and that there are 2 options:

1. To have radiotherapy which will shrink the tumour and extend life (but not cure the cancer), and that there are side effects
2. To have specialist palliative care treatment – to control pain and other symptoms, possibly at the local hospice

Sally does not seem to understand what Dr Michaels has told her, she comes confused and upset

Dr Michaels give support to Sally to MAXIMISE HER ABILITY to make decisions

Dr Michaels asks Kim to explain the options to Sally in her own words

- He asks Sally what is upsetting her
- Sally says she does not understand why he is not giving treatment that will make her better and that she does not want to leave her home

Kim explains that Sally sometimes takes a while to understand complicated situations, and hates being rushed

Presumes Sally has Capacity

Recognises Sally has not understood the information

Dr Michaels recognises that Kim knows how to communicate with Sally, so uses her to relay information in a meaningful way, to enhance Sally’s understanding

Dr Michaels spends time understanding what Sally’s concerns are
As the decision does not need to be made immediately, Dr. Michaels gives Sally and Kim some easy-to-read leaflets about both options to take away.

He arranges for her Macmillan nurse, Jane, to visit at home to discuss how she feels, so to give her some time and help her feel less pressured at home.

By using information leaflets, it means Sally can revisit information without time pressures.

Supporting Sally to make her own decision at her own pace.

The following week, Jane informs Dr. Michaels that she visited Sally. Sally was able to explain to Jane her understanding of her disease progression. She has made the decision that she doesn’t want any more active treatment and would prefer to go to the hospice when the time comes, but wants to stay at home for as long as she can.

Supporting Sally to make her own decision at her own pace, in a way that is meaningful to her has allowed her to maximise her ability to make a decision about her medical care.

All paragraph numbers in the vignettes refer to the GMC’s guidance *Treatment and care towards the end of life: good practice in decision making* (2010).

Dr. Michaels starts with the presumption that Sally has capacity to make the decision in question (Paragraph 11).

Helping Sally to understand her options and make a decision (Paragraph 12).

Involving Kim and Sally’s Macmillan nurse in the discussion to help support Sally (Paragraph 17-21, 22).

Not allowing assumptions about Sally’s learning disability to affect the treatment she is offered (Paragraph 44-46).