

# Using shared decision making approaches in haematology

The MAGIC team – Newcastle

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*This case study briefly describes how the team in Newcastle working on the Health Foundation's MAGIC programme to implement shared decision making developed shared decision making to discuss treatment options with haematology patients needing critical care support.*

## **Background**

There has been an increase in the number of bone marrow transplants done in the Newcastle Upon Tyne Hospitals NHS Trust, in particular 'higher risk' bone marrow transplants that carry an increased risk of morbidity and mortality. Some of these patients will need critical care support, either before transplantation, during the immediate engraftment period, or following development of complications post transplantation such as Graft Versus Host Disease.

Whilst patients fully consent to the bone marrow transplant procedure itself, historically there has been less discussion about intensive care. There is a recognised subset of high risk patients for whom a trial of critical care will be instituted, but a prolonged admission and multi-organ support may not be considered to be in the patient's best interests.

## **Shared decision making discussions: potential admission to ICCU**

One of the intensive care consultants now reviews the high risk transplant patients on the haematology ward. Discussion is patient-led and focuses on expectations of treatment and short and long term personal goals and values. There is discussion about what an admission to intensive care involves, and what that would mean to the person and their family; and what they think intensive care could offer (treatment options; pros and cons of treatment and chance of survival; physical, emotional and spiritual support). At November 2012, seven patients have been reviewed (one third of all the bone marrow transplant patients over the working time).

## **Capacity to make decisions – involving relatives**

Relatives are involved in a conversation about decision making for ongoing treatment options if the person is failing to improve or is deteriorating, as well as decision making where the patient may lose capacity to make informed decisions about their treatment and care. We use a framework for talking to a person's relatives when they lack capacity for decision making themselves. This framework is discussed with the patient.

## **Current framework for shared decision making on intensive care where the patient lacks capacity for decision making**

This framework was initially used for discussions around end of life care but is being used increasingly for daily discussions/updates with relatives.

The following headings act as an aide memoire to guide discussions with the person's relatives:<sup>1</sup>

- Discuss the nature of the decision
- What are the treatment alternatives?
- What are the pros and cons of treatment(s)?
- Uncertainty: what is the likelihood of success?
- What does the family understand about the treatment?
- What is known about the patient's preferences or values?
- What role should the family play in making the decision?
- Need for input from others: is there anyone else the family would want to be involved?
- Context of the decision: how could it affect the patient's life?
- What does the family think is the most appropriate decision?

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<sup>1</sup> DB White *et al.* Towards shared decision making at the end of life in intensive care units: opportunities for improvement. *Arch Internal Med* 2007; 167: 461-467.

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## Example of text for ‘points of view flyer’ to help inform the relatives of people who are admitted to the intensive care ward:

- Sometimes patients in intensive care cannot make decisions about their treatment because they are too sick to understand, retain and weigh up the information to come to a decision about they would want to happen.
- In this situation the medical team looking after the patient will take decisions on their behalf, taking into account any particular preferences they may have expressed for their treatment.
- Families are a key part of this process as they may be able to identify particular wishes that their loved one would want to be upheld.
- When you meet with the consultant she/he will discuss your relative’s progress with you, including any decisions to be made about their treatment and potential treatment options (including the pros, cons and likelihood of success); and what the overall decision(s) means for your relative. They will explain your role in decision making, help you to identify any particular wishes or values your loved one may have expressed and discuss what support is available for you in this difficult time.

## Sharing the learning

The consultant lead has presented this work at a recent conference held at Northumbria University “*Master Class in Critical Care for the Cancer Patient*”