Faculty of Medicine

Year 3

FOUNDATIONS OF CLINICAL PRACTICE

GE/DE course

Medical Ethics

Student Guide

2011/12

**Course Leader:** Dr Adrian Raby

**Course Lecturer:** Dr Wing May Kong

<https://education.med.imperial.ac.uk>

Medical Ethics

**SOLE** 3

[**Introduction** 5](#_Toc300759535)

[**The Course** 6](#_Toc300759536)

[Session summary 9](#_Toc300759547)

[Groups 10](#_Toc300759548)

[**Session 1** 13](#_Toc300759549)

Lecture: Introduction to medical ethics, autonomy, truth telling
and confidentiality [13](#_Toc300759550)

[**Session 2** 27](#_Toc300759551)

[Tutorial: Case discussion on Autonomy 27](#_Toc300759553)

[Lecture: Mental Incapacity, disability and rights 56](#_Toc300759556)

[**Session 3** 65](#_Toc300759557)

[Tutorial: Mental incapacity, critical reading session 68](#_Toc300759558)

[Lecture: Ethics in the treatment of children 95](#_Toc300759559)

[**Session 4**
Bone marrow harvesting debate 105](#_Toc300759560)

[**Session 5**  109](#_Toc300759561)

[**Session 6** 111](#_Toc300759562)

[Tutorial: Professionalism, cultural diversity](#_Toc300759564) [and the GMC 112](#_Toc300759565)

[Lecture: Ethics at the end of life 103](#_Toc300759566)

[**Session 7**  141](#_Toc300759568)

 [Group PBL assignment 142](#_Toc300759569)

 [Group PBL Presentation Assessment Form 145](#_Toc300759570)

 [Lecture: Resource Allocation 149](#_Toc300759573)

 [Lecture: Ethical theories, revision and preparing for the exam 154](#_Toc300759574)

[**Appendix 1: Guide to Tutorial Rooms** 161](#_Toc300759575)

**SOLE Feedback – Medical Ethics**

The following two pages provide you with templates on which you can record your thoughts as the course proceeds. At the end of the course you can enter your views on to SOLE.

**Please answer all questions by selecting the response which best reflects your view. After the questions there is an opportunity to comment on any aspects about which you feel strongly.**

 **N/A Strongly Agree Neutral Disagree Strongly
 agree disagree**

#### 1. By the end of the course, I think the aims and □ □ □ □ □ □

#### objectives will have been met.

#### 2. Teaching and learning opportunities (e.g. lectures, □ □ □ □ □ □small groups) for this course are suitable.

#### 3. Appropriate resources (e.g. books.) are available □ □ □ □ □ □for this course.

#### 4. Appropriate support materials (e.g. handouts, □ □ □ □ □ □web pages) are available for this course.

#### 5. I receive sufficient guidance and feedback. □ □ □ □ □ □

#### 6. The workload on this course is manageable. □ □ □ □ □ □

#### 7. Overall I am satisfied with this course. □ □ □ □ □ □

**If you wish to make further comments about this course, please use the space below.**

SOLE feedback – individual lecturers and tutors

**For each of the lecturers below, let us know whether or not you agree with the statement “Overall I am satisfied with this lecturer”. In particular, we want to know whether the lectures/tutorials were well structured and whether concepts were explained clearly.**

Although this template provides you the opportunity to record your comments about each lecture, in SOLE a lecturer’s name will only appear once.

The names of the tutors of small groups will appear on SOLE, so please make a note of your tutor’s name and your comments on the reflective evaluation forms at the end of each tutorial.

**At the bottom of this page, you will have an opportunity to comment on any aspects about which you feel strongly.**

**(Overall rating for how useful the session was)**

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Lecturer** |  | **N/A** | **Strongly****agree** | **Agree** | **Neutral** | **Disagree** | **Strongly****disagree** |
| **Session 1**Dr Adrian Raby | Intro to ethics, autonomy, truth, confidentiality |  |  |  |  |  |  |
| **Session 2**Dr Wing May Kong | Mental Incapacity, disability and rights |  |  |  |  |  |  |
| **Session 3**Dr Adrian Raby | Ethics in the treatment of children  |  |  |  |  |  |  |
| **Session 6**Dr Adrian Raby | End of life |  |  |  |  |  |  |
| **Session 7**Dr Adrian Raby | Resource allocation, healthcare and justice |  |  |  |  |  |  |
| Dr Adrian Raby | How to prepare for the exam and construct ethical arguments |  |  |  |  |  |  |

If you wish to make further comments, please use this space:

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Group** | **Tutorial** | **N/A** | **Strongly****agree** | **Agree** | **Neutral** | **Disagree** | **Strongly****disagree** |
|  | 1: Autonomy |  |  |  |  |  |  |
|  | 2: Mental incapacity |  |  |  |  |  |  |
|  | 3: Children  |  |  |  |  |  |  |
|  | 4: Professionalism |  |  |  |  |  |  |
|  | 5: Group presentations  |  |  |  |  |  |  |

## **Introduction**

This course is your foundation teaching in medical ethics. The present course is the backbone of knowledge and reasoning skills which you will use in your medical learning and professional career. You will apply the knowledge and skills you acquire in this course throughout the rest of your education and career, but in particular, you will receive specific ethics and law teaching at a number of points in the later medical curriculum – especially in Year 5’s General Practice and Primary Health Care attachment/course, the Paediatrics, Psychiatry and Obstetrics and Gynaecology rotations, and in the Year 6 “Practical Medicine” course. Your Year 6 PACES will include an Ethics and Law component. The Law course runs in parallel in year 3, and will take the form of on line learning modules supplemented by interactive lecture sessions during the Autumn term.

The General Medical Council requires all medical students to study medical ethics and law. It requires this for two main reasons: firstly, to ensure that doctors are well-informed and capable of practising medicine effectively, safely and lawfully; secondly, to ensure that their medical education is well-rounded and that students have a good grasp of the “human side of medicine” – the ways in which medicine is an art as well as a science, and the importance of respect, empathy and understanding in daily clinical practice.

The Institute of Medical Ethics has drawn up a core content of learning in consultation with the GMC, Medical Schools Council, PMETB (post graduate medical education board) and Royal Colleges, outlining the necessary skills, knowledge and behaviour for tomorrow’s doctors. The topics are as follows:

1. Foundations of medical law and ethics – ethical reasoning and legal frameworks
2. Professionalism and Good Medical Practice
3. Patients: their values, narratives, rights and responsibilities
4. Informed decision making, valid consent and refusal
5. Capacity and incapacity
6. Confidentiality
7. Justice and public health
8. Children and young people
9. Mental Health
10. Beginning of life
11. Towards the end of life
12. Medical research and audit

The full document is available on Blackboard. Your medical ethics and law teaching and assessment at Imperial is mapped to this core content of learning.

**Adrian Raby MA, MRCGP**

**Course Leader**

**Wing May Kong MA, PhD, FRCP**

**Vertical Theme Head Ethics, Professionalism and Leadership**

## **The Course**

The Year 3 course is given through a combination of lectures, small group ethics tutorials and Blackboard quizzes. The summative assessment is in the summer term of Year 3. You must pass this paper to go on to Year 4/5.

### **Attendance**

**The small group ethics tutorials are compulsory. Your tutor will take a register at the beginning of each tutorial.** Attendance and punctuality are important aspects of professional behaviour and we take these very seriously. Students who are unavoidably absent should email Dr Adrian Raby and Kate Woodhouse at the earliest opportunity (preferably before the tutorial itself). All absent students will have a note placed in their FEO files.

### **Small Group Ethics Tutorials**

**Aims**

* Raise awareness of ethics in clinical practice
* Recognise and learn to critically analyse value judgements in clinical practice
* Learn to reflect on personal values and attitudes
* Learn how to present arguments in a logical and coherent way
* Develop group working skills
* Learn the importance of group discussion in resolving ethical dilemmas
* Learn how ethical reasoning complement clinical knowledge in medical practice

You should have done the background reading and preparation **prior** to each tutorial. Full details including the background reading are in the guide under the relevant sessions. Tutorial notes summarising the key ethical arguments for each session will be released on Blackboard following each tutorial.

Your tutors are senior clinicians who as well as acting as facilitators, will be able to bring their own experience to the tutorials and show how awareness and understanding of ethical issues are vital to good decision making in medicine.

Good group working skills are essential to being a good doctor. In these tutorials you will develop your skills of listening, reflecting and responding to differing viewpoints and working effectively in a group to develop your ideas and conclusions.

### **Group Problem Based Learning Assignment**

In session 7 you will present your group Problem Based Learning (PBL) assignment. This forms your compulsory formative assessment (see below) for the course. Tutors are not expected to help students put together their PBL presentations. There will be an element of peer assessment for this assignment.

### **Reflective Evaluation and Feedback**

At the end of each tutorial you will be asked to spend 2 minutes to complete a reflective evaluation (in this guide). These are an important aspect of self directed learning. You will be asked to identify what you have learnt, what learning needs you have identified as a result of the session and how you will address those learning needs. Following the session you are asked to upload your reflections onto the ePortfolio on Pebblepad.

### **Learning resources – Blackboard learning**

The tutor guide and lecture notes are available on Blackboard (<http://learn.imperial.ac.uk/>). This virtual learning platform can be accessed from any PC/laptop with internet access. However, the NHS firewalls in some Trusts may make access quite slow. Within each session there will be links to useful websites as well as scanned electronic versions of the reading material for the tutorials.

A discussion board has been set up on Blackboard for the course. I will be the facilitator for the discussion board. If you have queries about the course content or assignments please post these on the discussion board. This means that the whole year can benefit from any responses and often students can answer a query amongst themselves. I will not respond to email queries unless they are about a specific personal issue.

### **Formative Assessment**

The formative assessment in ethics is a compulsory part of the course and takes the form of a group Problem Based Learning (PBL) assignment (see session 7 for details). For the assessment you will work in a group to produce both an oral presentation with accompanying Powerpoint slides.

### **Formative assessment deadline summary**

The formative assessment work must be submitted via Blackboard by **midnight Monday 12September**. **Only PBL group leads will be able to submit the formative assessment work**. Any requests to change the PBL group lead ***must be emailed to me no later than 0900 on Friday 9 September***. The PBL group leaders are shown in **bold** on the lists on page 11.

### **Summative Assessment**

The summative assessment in ethics is at the beginning of the summer term of Year 3 as part of the Year 3 FOCP paper. Students must pass this paper to proceed on the medical course.

The end of year exam (the FOCP summative assessment) will be a 75 minute modified essay question covering, Ethics, Personal and Professional Development and Clinical Communications. The exam format will be discussed at the end of session 7. The exam aims to assess reasoning and understanding rather than recall and knowledge and you will be allowed to bring in up to 20 single sided A4 pages of notes to the exam. The ethics questions comprise 30 minutes of the 75 minute paper. An example paper with model answers is available on Blackboard.

### **SOLE Feedback**

The student on-line evaluation (SOLE) is an invaluable way for us get your feedback on our teaching material, teaching methods and tutors. We are continually looking at ways in which to improve the teaching and teaching materials. We take you feedback very seriously and significant changes have been made to ethics and law teaching at Imperial in response to previous feedback.

The SOLE evaluation usually opens towards the end of each term. Therefore, please take a few minutes after each session to make some feedback notes for both your lecturers and tutors (please see the SOLE section at the beginning of this guide). You will then be able to refer to these notes when you in fill in the SOLE evaluation on-line later in the term.

### **Reading List**

**Core Text**

Jonathan Herring *Medical Law and Ethics*: 3rd edition, Oxford University Press 2010

All lecture notes will be on Blackboard. We’ll also post a list of useful references and links for each lecture. You will need the core text to support the material in the lectures, tutorials and Blackboard self directed learning.

**Additional Reading**

Hope RA, Savulescu J, Hendrick J Medical Ethics and Law – the Core Curriculum: (2003) Churchill Livingstone

Tony Hope Medical Ethics A very short introduction: Oxford University Press,
1st edition 2004. A very accessible and short introduction to medical ethics

L Schwartz, PE Preece, RA Hendry. Medical Ethics a Case Based Approach: Edinburgh, WB Saunders, 2003

C Baxter, M Brennan, Y Coldicott, M Moller *Medical Ethics and Law*: PasTest,
2nd Edition 2005

H. Kuhse and P Singer (eds) *Bioethics An Anthology*: Blackwell 2001

**Supplementary reading**

The following books provide accessible but more in depth philosophical analysis

P Benn *Ethics*: Routledge, 2002

R Gillon *Philosophical Medical Ethics*: John Wiley, 1985

J Harris *The Value of Life*: Routledge, 1991

J Jackson *Ethics in Medicine*: Polity Press, 2006

B Jennet *The Vegetative State*: Cambridge University Press 2002

**Websites**

See especially: <http://www.bma.org.uk/> (The BMA website, which has most BMA guidance downloadable free), <http://www.gmc-uk.org/> (The GMC website, which has most of the General Medical Council’s official guidelines), <http://jme.bmjjournals.com> (the website of the Journal of Medical Ethics). Most ethics websites aren’t worth the bother, but sometimes you uncover gems. Handle with care, as you would any website purporting to give medical information! In particular, much information on the net is American in origin, and may be misleading about UK law, and have somewhat different emphases, as US medicine is largely in the private sector. Nonetheless, we can recommend the useful “Virtual Mentor” site run by the American Medical Association: <http://www.virtualmentor.org/>

## **Session summary**

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Date** | **Topic** | **Room** |
| **1** | **Monday 5th September**  |  |
| 11:30-12:30  | Lecture: Introduction to medical ethics, autonomy, truth telling and confidentiality | GLT |
| 12:30-13:00 | Self directed study: preparation for session 2 |  |

|  |  |  |
| --- | --- | --- |
| **2** | **Tuesday 6th September**  |  |
| 09:30-10:30  | Tutorial: Case discussion on autonomy  | G1, G2, G3, R2, R3 |
| 10:45-11:45  | Lecture: Mental incapacity, disability and rights  | GLT |
| pm | Preparation for session 3 |  |

|  |  |  |
| --- | --- | --- |
| **3** | **Wednesday 7th September** |  |
| 09:00 - 10:00  | Tutorial: Mental incapacity, critical reading session | 4 Comms Rooms, A B C D, PBL1 |
| 10:30-11:30 | Lecture: Ethics in the treatment of children  | GLT |
| 11:30-13:00 | Self directed study: preparation for session 4 |  |

|  |  |  |
| --- | --- | --- |
| **4** | **Friday 9th September**  |  |
| 14:00-15:30 | Tutorial: Bone marrow harvesting debate | G1,G2,G3 Comms rooms A & B |
| 15:30-17:00 | Self directed study: Preparation for session 6 and 7 |  |

|  |  |  |
| --- | --- | --- |
| **5** | **Monday 12th September** |  |
|  | Preparation for session 6 and 7Submit presentation for Session 7 by midnight 12th Sept |  |

|  |  |  |
| --- | --- | --- |
| **6** | **Tuesday 13th September**  |  |
| 09:30-10:30 | Tutorial: Professionalism, cultural diversity and the GMC | G1, G2, G3, R2, R3 |
| 10:45-11:45 | Lecture: ethics at the end of life | GLT |
| 12:00-13:00 | Final preparation for session 7 |  |

|  |  |  |
| --- | --- | --- |
| **7** | **Tuesday 13th September** |  |
| 14:00-15:00 | Tutorial: Group presentations  | G1, G2, G3, R2, R3 |
| 15:15-16:00 | Lecture: resource allocation, healthcare and justice | GLT |
| 16:00-16:30 | Lecture: Constructing ethical arguments and preparing for the exam | GLT |

## **Groups**

For the tutorials you will be in the following groups.
You will be sub-divided into A, B, C, as shown, with your group leader in bold.
The role refers to Session 4.

**Group 1**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  |  | Group | Role |
| **Dr** | **Hind** | **Al-Qassab** | A | Enya’s mother |
| Mr | Edward | Amiry | A |  |
| Mr | James | Arthur | A |  |
| Miss | Paige | Barrows | A |  |
| Miss | Aliya | Bryce | A | Zeno’s mother |
| **Ms** | **Sophie** | **Chambers** | B |  |
| Miss | Kristen | Foxwell | B |  |
| Mr | Douglas | Burke | B |  |
| Mr | James | Gilbert | B | Zeno’s father |
| Miss | Arvinder | Athwal | B |  |
| Miss | Harriet | Davidson | B |  |
| **Miss** | **Sonja** | **Foo** | C |  |
| Mr | Andrew | Owusu-Agyei | C |  |
| Miss | Shanika | Basnayake | C | Enya |
| Mr | Alexander | Yao | C |  |
| Ms | Esther | Chan | C |  |
| Miss | Kani | Varshneya | C |  |

**Group 2**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Miss** | **Vinothini** | **Manivasagam** | A | Enya’s mother |
| Miss | Oshini | Shivakumar | A |  |
| Miss | Sophie | Aylett | A |  |
| Miss | Velicia | Bachtiar | A |  |
| Mr | Johnson | Chen | A | Zeno’s mother |
| Miss | Frances | Conti-Ramsden | A |  |
| **Miss** | **Suny** | **Coscione** | B |  |
| Mr | Kaveesh | Dissanayake | B |  |
| Miss | Rosanna | Baker-Wilding | B | Zeno’s father |
| Miss | Sophie | Boyd | B |  |
| Mr | Benjamin | Cullinger | B |  |
| Dr. | Georgina | Fenwick | B |  |
| **Mr** | **Nicholas** | **Hayward** | C |  |
| Miss | Nina | Kumari | C | Enya |
| Mr | Gary | Tse | C |  |
| Mr | Bahig | Aziz | C |  |
| Miss | Linnea | Ek | C |  |
| Miss | Hannah | Gould Brown | C |  |

**Group 3**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Miss** | **Joanna** | **Poole** | **A** | Enya’s mother |
| Mr | Alain | Chaglassian | A |  |
| Dr. | Anthony | Dorr | A |  |
| Mr | Alexander | Presland | A |  |
| Mr | Terry | Evans | A | Zeno’s mother |
| Mr | James | Iliff | A |  |
| **Mr** | **Robert** | **Mitchell** | **B** |  |
| Miss | Emma | King | B |  |
| Mr | Alexander | McFarquhar | B | Zeno’s father |
| Miss | Annie Pan | He | B |  |
| Mr | Julian | Hong | B |  |
| Ms | Ruhella | Hossain | B |  |
| **Miss** | **Marie** | **Houdmont** | **C** |  |
| Miss | Sarah | Hough | C | Enya |
| Miss | Emma | Kenney-Herbert | C |  |
| Ms | Helen | Nightingale | C |  |
| Miss | Kalliste | Oh | C |  |
| Miss | Juliet | Zani | C |  |

**Group 4**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Miss** | **Maleeha** | **Munnawwar** | A | Enya’s mother |
| Miss | Christie | Noble | A |  |
| Miss | Alexa | Prichard | A |  |
| Miss | Jalpa | Kotecha | A |  |
| Mr | Huy Quang | Nguyen | A | Zeno’s mother |
| Miss | Alice | Page | A |  |
| **Miss** | **Payal** | **Dube** | B |  |
| Miss | Krsna | Mahbubani | B |  |
| Miss | Fakhirah | Badrulhisham | B | Zeno’s father |
| Miss | Charlotte | Holdsworth | B |  |
| Mr | Aminul | Islam | B |  |
| Miss | Ines | Lolosidi | B |  |
| **Mr** | **Foad** | **Mohamed** | C |  |
| Mr | Anas | Nader | C | Enya |
| Miss | Mohana | Ratnapalan | C |  |
| Ms | Anna | Robinson | C |  |
| Miss | Nadja | Oertelt | C |  |

**Group 5**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Miss** | **Faraa** | **Karim** | A | Enya’s mother |
| Mr | Kishan | Tailor | A |  |
| Miss | Rachel | Swain | A |  |
| Dr | Anna | Sher | A |  |
| Miss | Sana | Rizvi | A | Zeno’s mother |
| Mr | Mohammad | Shahzad | A |  |
| **Mr** | **Paramvir** | **Sawhney** | B |  |
| Mr | David | Townsend | B |  |
| Mr | Mohammed | Younas | B | Zeno’s father |
| Miss | Sarah | Young | B |  |
| Miss | Hayley | Jones | B |  |
| **Miss** | **Dawn** | **Thompson** | C |  |
| Ms | Binta | Umar | C |  |
| Mr | Dominic | Yelling | C | Enya |
| Mr | Yu | Zhang | C |  |
| Miss | Folasade | Onakoya | C |  |
| Miss | Zoe | Young | C |  |

**Session 1 Monday 5 September 2011**

|  |  |  |
| --- | --- | --- |
| 1130 – 1230 | Lecture: introduction to medical ethics, autonomy, truth telling and confidentiality | Glenister Lecture Theatre |
| 1230 – 1300 | Self-directed study: preparation for session 2 |  |

### **Essential Reading**

**Lecture reading**

‘Consent to treatment’ in *Medical Law and Ethics*. J.Herring, 3rd Ed. 2010, Oxford University Press. Chapter 4: section 11 ‘Ethics and autonomy’ (pp124-132).

‘Ethical and Legal Background’ in ‘Medical Ethics and Law. The Core Curriculum’ T.Hope, J. Sauvelescu, J. Hendrick’ 2nd Ed. 2008, Churchill Livingstone. Chapters 1 and 2

‘Confidentiality’ in *Medical Law and Ethics*. J.Herring, 3rd Ed. 2010, Oxford University Press. Chapter 5: Introduction (pp213-215), section 8 ‘ethical issues’ (pp255-260)

Autonomy tutorial notes – released on Blackboard after today’s session

**Tutorial Reading**

*‘*Physician recommendations and patient autonomy; finding a balance between physician power and patient choice’ T.E.Quill and H. Brody. *Annals of Internal Medicine*1996;125(9):pp763-769 <http://www.annals.org/cgi/content/full/125/9/763>

‘Pressuring Mrs Thomas to accept treatment: a case history’ B.Hurwitz. *Journal of Medical Ethics* 1998;24:pp320-321

**Additional reading**

‘*The Value of Life. An introduction to medical ethics*’ J.Harris 1985 Routledge. Chapter 10 ‘Respect for Persons I’;pp192-205.

‘African American patients’ perspectives on medical decision making’ A.M.Torke, G.M. Coprbie-Smith, W.T.Branch Jr *Archives of Internal Medicine.* 2004;164(5):pp525-530 <http://archinte.ama-assn.org/cgi/content/full/164/5/525>

*Bioethics an Anthology*, Kuhse and Singer (eds) Part IX, Chapter 64, pp507-512. R.Higgs ‘On telling patients the truth’

**!! Course work to be completed before Tuesday 6th September !!**

Reading for session 2 tutorial (see above)

**Lecture: Introduction to medical ethics, autonomy, truth telling and confidentiality**

 **Glenister Lecture Theatre 11:30-12:30**

**Learning objectives**

Following this session you should be able to:

* Describe what is mean by the term ‘medical ethics’?
* Explain is meant by autonomy and why it is important
* Evaluate how respecting autonomy translates into clinical practice
* Consider whether doctors should always tell the truth?
* Be familiar with the ethical basis of confidentiality
* Describe situations where breaching confidentiality may be permissible

**Ethics is:**

**Morality is:**

**Medical ethics is:**

**Why study ethics?**

The practice of medicine is an art

Serves as a framework for understanding basic duties and responsibilities required for good medical practice

Facilitates reflective and critical reasoning in the medical context

To stop yourself getting sued

GMC requirement

**Autonomy**

**Ms B**

43 year old social worker

Suffered haemorrhage within the spinal cord, leaving her permanently paralysed from the neck down

Dependent on artificial ventilation to stay alive

Told the staff in ITU that she did not want to continue living in this state and requested

that the ventilator be switched off

ITU staff refused

Ms B agreed to course of antidepressants

6 months later still requesting that ventilator be switched off

Assessed by 2 independent psychiatrists.

Mentally competent and not depressed.

Staff argued that Ms B could not make a properly informed decision until she had spent some time in a specialist rehabilitation unit

**Question 1**Do you think in the circumstances that the ITU doctors should have switched off the ventilator?

Yes No Don’t Know

***Explain your decision***

**Ms B – The decision**

President of the Family Division ruled that continuing to ventilate Ms B in the face of her competent refusal was unlawful and the ventilator must be switched off even if this would result in her inevitable death

***Was the decision ethically acceptable?***

**Why Study Medical Ethics?**

To practice medicine better

To make medical practice better

Ethics is an integral part of all clinical encounters and medical interventions

Sound ethical reasoning are fundamental to the ongoing evolution of medical law, professional values and health policy

**Autonomy**

‘*The right to determine what shall be done to one’s own body is a fundamental right in our society. The concepts inherent in this right are the bedrock upon which the principles of self-determination and individual autonomy are based*’

*Ms B and an NHS Hospital Trust (2002) quoted from Re T (Adult refusal of treatment) [1992] 4 ALL ER (CA)*

***What is autonomy?***

**Autonomy**

***Why is autonomy important?***

**Instrumental value**

Autonomy has instrumental value since:

***Can a ‘bad choice’ sometimes be the right choice?***

***Yes, because….***

**What if I make bad health related choice?**

What about

Smoking?

Eating cream cakes?

Base jumping?

**Health v Well-being**

***A bad health choice may still be in my overall best interests because:***

**What if I make *REALLY* bad choices?**

Demand that my ventilator be switched off

How can death be in my best interests?

**The experience machine**

"Suppose there were an experience machine that would give you any experience you desired. Superduper neuropsychologists could stimulate your brain so that you would think and feel you were writing a great novel, or making a friend, or reading an interesting book. All the time you would be floating in a tank, with electrodes attached to your brain. ….Would you plug in? What else can matter to us, other than how our lives feel from the inside?" *Robert Nozick ‘Anarchy,State and Utopia’*

***Would you plug in?***

**The intrinsic value of autonomy**

***Autonomy has intrinsic value because:***

1.

2.

3.

**Respecting autonomy in medical practice**

Respecting autonomy does not simply mean handing over decision making to the patient

***Autonomous choices require:***

1.

2.

3.

***Respecting autonomy means enabling patients to make autonomous choices through:***

1.

2.

3.

4.

5.

**Respecting autonomy requires us to provide a reasonable range of choices**

**Autonomy and Medical Care**

***Respecting autonomy is likely to improve medical care by:***

1.

2.

3.

4.

5.

**Examples of coercion in medical practice:**

* Refusing to operate unless a patient complies with advice
* Using scare tactics to influence a patient’s decision
* Using guilt to influence a patient’s decision
* Pressurising a patient

**Are there any limits to autonomy?**

**Limits to Autonomy**

*‘the only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others. His own good either physical or moral is not sufficient warrant’*

 *J.S. Mill, ‘Utilitarianism, On Liberty and Considerations on Representative Government’*

**Justice and limits to autonomy**

We live in a society that values autonomy highly

Treating others as equals requires us to respect autonomy equally

***Therefore…***

**What constitutes harm to others?**

Drink Driving

Passive smoking

**What about:**

Excessive burdens on family members?

Excessive use of health care resources because of lifestyle choices?

Forcing doctors to act against their moral conscience?

**Conflicting duties**

* Duty to benefit the patient (beneficence)
* Duty not to cause unnecessary harm (non maleficence)
* Duty to ensure fair distribution of resources (justice)

**Paternalism and truth telling**

***What is paternalism?***

**Arguments sometimes used to justify paternalistic dishonesty**

Technical information is difficult to put across – patients may not understand or may put undue weight on rare complications of treatment

***But…***

Doctors face uncertainty – life expectancy or outcome of a treatment may be unpredictable

***But…***

The patient might not be able to handle the information – might make him worse ‘what you don’t know can’t hurt you’

***But…***

Is withholding the truth better than lying?

**Yes, because:**

1.

2.

3.

4.

5.

***No, because:***

1.

2

3.

4.

**Withholding information is rarely justified**

***Because:***

1.

2.

3.

4.

**Summary**

Respecting autonomy promotes best interests and is essential to human flourishing

Autonomy has intrinsic value as well as promoting best interests

Respecting autonomy is likely to improve outcomes in medicine

Respecting patient autonomy does not mean simply transferring decision making to patients

Respecting autonomy is inherently linked to truthfulness, but judgment may need to be exercised

**CONFIDENTIALITY**

Four different ethical arguments

* 1. Utilitarian
	2. Autonomy
	3. Duty
	4. Virtue

**Confidentiality and Consequences**

Whether or not an action is morally acceptable is solely determined by its consequences

**Confidentiality and Consequences**

Patients are generally happy to disclose personal information because they trust doctors to keep their information confidential

It is essential that patients disclose personal information for doctors to treat them appropriately

If doctors frequently breached confidentiality, patients would lose trust.

As a consequence patients would be unwilling to disclose personal information

**Weaknesses of the consequentialist arguments (counter arguments)**

1.

2.

**Case 1**

A GP sees Ms R, a young woman with recurrent genital warts. During the consultation she mentions that she is trainee solicitor. It turns out that she is working for his wife.

That evening, the GP tells his wife about Ms R. His wife tells no one else.

***Is this ethically acceptable?***

**Confidentiality and Autonomy**

Respecting autonomy should be seen as a fundamental principle in medical ethics. Therefore an action that does not respect autonomy is not morally acceptable whatever the outcome (unless there is a justifiable reason for limiting autonomy)

**An autonomy based argument for respecting confidentiality**

1. Individuals consider it very important that they control who has access to their personal information

Therefore:

2.

3.

***However it may be ethically justified to breach confidentiality if…***

***However…***

**Problems with a autonomy based approach**

This approach does not help us in situations involving:

1.

2.

3.

**Case 2**

Mr K, the former head of surgery, is brought into hospital following a car crash. He is wearing lacy knickers and a suspender belt. He dies in A+E soon after arriving.

The next day you bump into a surgeon who used to work with him and tell him about Mr K’s choice of underwear. ***Is this ethically acceptable?***

**Confidentiality and Duty**

Certain actions are morally required and others are morally impermissible whatever the outcome *ie* we have certain moral duties.

When a doctor gains personal information about a patient there is an implied promise that this information will be kept confidential

There is a moral duty not to break promises

The duty is owed to ALL your patients

Therefore it is wrong to breach confidentiality unless we are given permission to disclose

**Problems with the duty based approach**

**1.**

**2.**

**3.**

**4.**

**Case 3**

Prosenjit Poddar meets Tatiana Tarasoff at the Unversity of California where they are both students. After a kiss on New Years Eve Prosenjit becomes infatuated with Tatiana, and believes that had a serious relationship, despite her telling him otherwise. Prosenjit becomes depressed and seeks the help of Dr Moore a psychologist. During session 9 Prosenjit tells Dr Moore that he is going to kill Tatiana when she gets back from the summer recess

**Serious crime – the duty argument refined**

The 2 parties to the promise of confidentiality are the doctor and patient

The doctor is a public servant

The patient is a public citizen

The patient has a moral duty not to commit serious crime

If the patient commits a serious crime has he breached the terms of the promise?

**Patients who lack capacity – the duty argument refined**

The implied promise to maintain confidentiality operates for ALL patients

However, with children and adults lacking capacity the doctor has an overriding duty to act in their best interests

***Therefore …***

***But…***

**Breaching confidentiality**

Breaching confidentiality may be ethically justified if:

1.

2.

3.

4.

5.

**But…**

**1.**

**2.**

**3.**

**4.**

**5.**

**What about?**

Protecting individuals from harm to themselves ***e.g.***

***Arguments for and against***

Disclosures that may damage the doctor patient relationship ***e.g.***

***Arguments for and against***

Preventing crime in general ***e.g.***

***Arguments for and against***

**THE GMC**

* Confidences must be respected.
* Consent by patient is the primary exception to the principle of keeping confidential information secret.
* But, where secrecy would risk death or serious harm to the patient or another, then disclosure is allowed.
* Patients should be told at the outset how information about them is to be used.
* Personal information can be disclosed in the public interest but this must be exceptional.

**Confidentiality in Practice**

Most breaches are inadvertent:

***e.g***.

1.

***Safeguards:***

2.

***Safeguards:***

3.

***Safeguards:***

4.

***Safeguards:***

5.

***Safeguards:***

**Summary**

The ethical duty to maintain confidences can be defended on consequentialist, autonomy and duty grounds

Each approach permits breaching confidentiality in certain situations

When considering whether it is appropriate to disclose confidential information you should reflect on the ethical arguments for and against breaching confidentiality

**Session 2 Tuesday 6 September 2011**

|  |  |  |
| --- | --- | --- |
| 09:30-10:30  | Tutorials: Case discussion on autonomy | G1, G2, G3, R2, R3 |
| 10:45-11:45  | Lecture: Mental incapacity, disability and rights | GLT |
| 12:00-13:00 | Preparation for session 3 |  |

**!! Course work to be completed before Wednesday 7th September !!**

* Reading for session 3 tutorial (see page 62 and session 3 reading list)
* Prepare group presentation of critical reading

**Essential reading**

See Essential Reading for tutorial under session 1 reading above

**Tutorial: Case discussion on Autonomy**

**Author:** Dr Wing May Kong

**Tutorial time:** 60 minutes

**Group teaching: tutors and rooms**

|  |  |  |
| --- | --- | --- |
| **Group** | **Tutors** | **Room** |
| 1 | Dr Paul Lewis | Glenister seminar room 1 |
| 2 | Professor Terry Cook | Glenister seminar room 2 |
| 3 | Professor Edwina Brown | Glenister seminar room 3 |
| 4 | Dr Andrew Lawson | Reynolds Building 1st floor R2 |
| 5 | Dr Linda Miller | Reynolds Building 1st floor R3 |

The purpose of small group work is to promote deep learning by encouraging active participation by all members in working on a clearly defined task. It provides a forum in which concepts can be clarified using skills such as explaining, listening, discussing, questioning, presenting and defending a position and giving feedback. You are expected to learn how to generate an ethical argument and defend it while responding to counter arguments from other group members.

Within each tutorial group students should be divided into 4 groups consisting of 2-3 students and each group assigned their question. Students should have already done the background reading and read the case studies and questions. As tutor, you will act as the facilitator as well as guiding the discussion. Time is relatively limited and the following format is suggested:

For the first session we have allowed an extra 15 minutes for the students to cover the background reading and case scenario. For the second session students will have had 15 minutes at the end of their lecture to do this reading prior to starting the session.

**5 minutes:** Ice breaking, nominate time keeper and scribe and assign groups

**10 minutes:** Discuss case, consider questions below, make notes,

**30 minutes:** Re-form tutorial group, each group to briefly present its arguments/points. Then as a group discuss whether, on the basis of this, it is reasonable for Dr Ross to lie to Maureen to keep her in hospital for a social services assessment.

**2 minutes:** Students complete reflective evaluation form (see appendix), Tutors please complete tutor feedback form (provided in tutorial rooms)

**10 minutes:** Feedback

**Case Scenario**

Maureen is an 80 year old retired music teacher. Until a year ago she was still giving private piano lessons in her home. She has osteoarthritis which has become much worse over the past year and now causes severe mobility problems. Maureen lives alone and struggles to maintain her independence. Her daughter, Jean lives 10 miles away in Ilford and comes every evening with the shopping and to help her wash and get into bed. Maureen has refused home help and meals on wheels by social services as she does not want to accept help from strangers. She has recently had several falls resulting in minor injuries and attendances at A+E. Jean is finding it difficult to manage and wants her mother to move in with her. Maureen says doesn’t want to move to Ilford; she has lived in her house for 60 years and has many friends nearby.

2 months later Maureen is in A+E following another fall. The A+E registrar, Dr Ross examines her. She needs stitches to her head but is otherwise well and can go home after the stitches. Maureen says that she would like to get back to her own home as soon as possible. Soon after, Jean telephones. Jean tells Dr Ross that her mother has been falling a lot and that it is not safe for her mother to go back to her own home. She explains that she wants her mother to move in with her but that her mother has always been very stubborn and will not listen to her. She asks if Dr Ross can arrange for social services to assess her mother as Jean is certain that they will agree that it is unsafe for Maureen to continue living on her own. Jean thinks that they may be able to change Maureen’s mind if social services and the hospital staff put pressure on her together. Dr Ross says that he has some concerns about Maureen’s safety at home. However, Maureen is clearly competent to make her own decisions and there are no medical grounds for keeping Maureen in hospital and she is adamant that she does not want any extra help. He thinks it unlikely that Maureen would agree to stay in hospital just for a social services assessment. Jean suggests that Dr Ross tells Maureen that she needs to stay in for observations and further tests and then get social services to assess her.

**Questions**

Assuming that Maureen is mentally competent:

**Group 1**

Discuss the arguments why it would be in Maureen’s best interests to move in with Jean

**Group 2**

Discuss the arguments why it would *not* be in Maureen’s best interests to move in with Jean

**Group 3**

Discuss the arguments in favour of limiting the weight given to Maureen’s autonomy

**Group 4**

Discuss the arguments against limiting the weight given to Maureen’s autonomy .

### **Reflective Evaluation**

Please take 2 minutes to respond to the following questions. Following the session these notes should be uploaded onto your ePortfolio on Pebblepad:

**1. What have I learnt from today’s tutorial?**

**2. What learning needs have I identified from today’s tutorial?**

**3. How will I address those learning needs?**

**Session 1 Reading**

**Physician Recommendations and Patient Autonomy: Finding a Balance between Physician Power and Patient Choice**

[Timothy E. Quill, MD, and Howard Brody, MD, PhD](http://www.annals.org/cgi/content/full/125/9/763#FN#FN)
**Annals of Internal Medicine, 1 November 1996 | Volume 125 Issue 9 | Pages 763-769**

<http://www.annals.org/content/125/9/763.full>

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Pressurising Mrs Thomas to accept treatment: a case history

Journal of Medical Ethics, 1998: 24, 320-21

<http://jme.bmj.com/content/24/5/320.full.pdf>

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*The Value of Life. An introduction to medical ethics* J.Harris 1985 Routledge.

Chapter 10 ‘Respect for Persons I’ pp192-205.

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*A Companion to Bioethics,* Kuhse & Singer, John Wiley and Sons, 2001,

Chapter 41, pp432-440, Higgs R. *‘*Truth telling’

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**Lecture: Mental Incapacity, disability and rights**

**Dr Wing May Kong Glenister Lecture Theatre**

 **1045 – 1145**

**Learning outcomes**

Following this session you should be able to:

Discuss whether and why human life is of special moral value

Discuss what is meant by a ‘right to life’ and who this right applies to

Reflect on the ethical issues raised in trying to determine ‘best interests’

**Mr A and Mr Z version 1**

Mr A is a 19 year old British student of Vietnamese origin with cardiomyopathy.

Mr Z is a 19 year old British student of English origin with cardiomyopathy.

Both will die in 3 months without a heart transplant. Both have a life expectancy of at least 10 years with a heart transplant

***One heart is available. Who should receive the transplant and why?***

**Mr A and Mr Z version 2**

Mr A is a 19 year old with Down’s syndrome and cardiomyopathy.

Mr Z is a 19 year old British student with cardiomyopathy.

Both will die in 3 months without a heart transplant. Both have a life expectancy of at least 10 years with a heart transplant

***One heart is available. Who should receive the transplant and why?***

**What do we mean by a ‘right’?**

Rights are a special form of moral claim

Legal right vs moral right

Who has rights ?

**…**

**…**

**…**

**What counts as a right?**

What counts as a moral right?

**Negative and positive rights**

Many rights are about what others may *not* do to us, ***e.g.***

However, positive rights dictate**…**

***e.g.***

**Do we have positive rights?**

What about?

Right to housing?

Right to welfare?

Right to fertility treatment?

***What do you think?***

***Or are they simply…..***

**Is there a ‘Right to life’ ?**

Does a right not to be killed imply a right to life?

***e.g.***

Is the right absolute?

***e.g.***

Who can claim this right?

Do ***some individuals have…***

**Healthcare - right or rhetoric?**

If healthcare is a moral right, this imposes an obligation on others to ensure adequate healthcare is provided to **all** humans

However, at a global level, who are these others with whom the obligation rests?

Without the institutions to deliver these obligations, a right to healthcare ***is…***

**Equal respect: Ms Y**

Ms Y is a 46 year old woman with severe learning disability and a mental age of 2. She has lived in residential care since the age of 15. She cannot speak and needs assistance with all aspects of self care. She has 3 sisters. She seems particularly close to her eldest sister whom she is always happy to see

In 2000 Ms Y’s oldest sister developed acute leukaemia. Her prognosis was extremely poor unless a suitable bone marrow donor could be found. Of her 3 sisters, only Ms Y was a suitable match.

Should Ms Y be a bone marrow donor for her sister?

**YES: A Consequentialist approach**

***1)***

***2)***

***Therefore***

**NO: Y has certain rights**

Ms Y has the same rights as her sister

***Right to***

***Right to***

Respecting an individual rights entails only acting in ways that benefit the individual

Therefore ***harvesting bone marrow is only acceptable…***

**Best interests**

Ms Y has a close relationship to her sister that is very valuable to Ms Y

In this situation the benefit to Ms Y of saving her sister’s life through a bone marrow transplant would mean that Ms Y was not simply being ‘used’ to save her sister’s life

In which case bone marrow should be harvested from Ms Y

**Best interests**

*Who* decides best interests?

*How* do we decide best interests?

**Best interests - Who decides?**

 ***1)***

***2)***

***3)***

***How* do we decide best interests?**

1) Wishes and values of the individual

***2)***

***3)***

***4)***

***5)***

***6)***

**A precedent right to decide?**

If a person loses autonomy through acquired mental disability *e.g.* head injury, dementia, should there be a precedent right (when autonomous) to determine future treatment or non treatment?

**Dworkin and advance decisions**

Ronald Dworkin has argued that autonomous individuals have an idea of how their lives should unfold and how their lives should end.

***Respecting autonomy requires…***

Therefore an individual’s ***previously stated autonomous wishes…***

**Advance decisions and the Mental Capacity Act**

Under the Mental Capacity Act Advance decisions drawn up when an individual is mentally competent are legally binding

It follows ***that there is a legal right to…***

**Mr E. Kenieval**

Mr E. Kenieval is a 42 year old motor cycle enthusiast. He is injured in a major accident and is in a coma for 2 weeks. There are initial concerns that he may not walk again.

However, after several operations and many months rehab he makes a full recovery.

Following this experience he draws up an Advance Decision with his lawyer stating that he refuses life sustaining treatment should he, for any reason, become incapacitated such that he is dependent on others for his daily needs with no meaningful prospect of recovery.

14 months later Mr Kenieval collides with a van at a roundabout

He suffers severe brain injury leaving him unable to talk or understand even simple commands.

He is now in a nursing home, dependent on others but seems quite happy

He develops a kidney infection, treatable with antibiotics

Without antibiotics he is likely to develop septicaemia and may die

**Should Mr Kenieval’s kidney infection be treated? *What do you think?***

***Do advance decisions give too much weight to the right to self determination?***

**Rights at the beginning of life**

Abortion is a criminal offence unless:

A) the pregnancy is ***less than 24 weeks*** and that the risks to the physical and mental health of the woman or any children in her family are greater if the pregnancy were continued

**OR**

At any stage of pregnancy if:

B) It is necessary to prevent grave and permanent injury to the mother **OR**

C) Continuing pregnancy would involve a greater risk to the life of the pregnant woman than termination **OR**

D) Substantial risk of serious physical or mental handicap

An abortion can be performed at ANY stage on the grounds of serious disability

Few conditions are so awful that the baby could be said to be ‘better off dead’

***Down’s syndrome accounts for***…

Does current law imply ***that those with disability …***

Is there an ethical difference between

Not wanting to be pregnant AND not wanting ***to be pregnant …***

Is terminating a pregnancy on the grounds of ***disability any different …***

Do these grounds imply that the ***lives of those with disability …***

***Do these grounds reinforce …***

**Disability – a social construct?**

Disability is only a problem ***because society fails …***

Parents of disabled children are ***often more worried about the …***

Parents worry about who will look after their child when they die

**Disability and maternal rights**

Having a severely disabled child can put immense physical, emotional and financial strain on parents

***Other children …***

Therefore, ***a woman should be able to …***

**Rights of the mother v rights of the unborn child**

Is talk of rights helpful?

Do rights based approaches encourage confrontation

Should we focus instead on the moral agent?

Judith Jarvis Thomson

**Disability, choice and Autonomy**

As moral agents ***mothers should …***

***Autonomous decisions should be …***

Autonomous choice ***requires that we are …***

If society fails to ensure justice and provide an adequate level of support for those with disability does a woman have a reasonable range of options?

**Has the law got it right?**

Is the law regarding abortion on the grounds of disability discriminatory?

Should the law provide clearer guidance on what constitutes ‘serious handicap’?

Does the binding nature of Advance Decisions unfairly override the rights of individuals lacking mental capacity?

**Public opinion**

Most people in the UK think abortion beyond 24 weeks on the grounds of serious disability should be lawful

But *if* this is discriminatory does ***public opinion and consensus provide….***

**A case**

Rev Joanna Jepson

**Policy implications**

If the law was more prescriptive as to what constituted a ‘serious handicap’ in ***terms of grounds for abortion could this …***

But does failing ***to do so leave the way open …?***

**Summary**

Rights are a strong ***moral claim that ….***

***But ….***

There is no consensus on whether rights exist or whether they are simply rhetorical tools

Nonetheless a ***rights based approach helps highlight …***

**Session 3 Wednesday 7 September 2011**

|  |  |  |
| --- | --- | --- |
| 09:00 – 10:00  | Tutorials: Mental incapacity, critical reading session | See below |
| 10:30 – 11:30 | Lecture: Ethics in the treatment of children  | GLT |

**!! Course work to be completed before Friday 9th Sept !!**

Read and prepare witness statements for session 4

**Tutorials: Mental incapacity**

|  |  |  |
| --- | --- | --- |
| **Group** | **Tutors** | **Room** |
| 1 | Dr Neeraj Sareen and Dr Lucy Hooper | Comms Room A  |
| 2 | Dr Alison Mears | Comms Room B |
| 3 | Professor Edwina Brown and Dr Adeel Ghaffar | Comms Room C |
| 4 | Dr Ana Almaraz | Comms Room D |
| 5 | Dr Charles Cayley | PBL1 |

**Learning Outcomes**

By the end of this tutorial students should be able to:

* Describe the relationship between autonomy and best interests with respect to decision making involving individuals with acquired mental incapacity
* Identify and concisely summarise the ethical arguments in the reading material
* Discuss the ethical arguments in the reading material
* Reflect on their own views on the ethical challenges raised by dementia in the light of this reading

**Tutorial Reading** *(to be completed BEFORE today’s tutorial)*

**All groups:**

‘Margo’s Logo’ A.D. Firlik. 1991, *JAMA*;256(2):p201

**Subgroup A:**

*Bioethics an Anthology*, Kuhse and Singer (eds) Part IV, Chapter 34, pp305-311. R.Dworkin ‘Life past reason’.

**Subgroup B:**

*Bioethics an Anthology*, Kuhse and Singer (eds) Part IV, Chapter 35, pp312-320. R.Dresser ‘Dworkin on dementia: elegant theory, questionable policy‘

**Subgroup C:**

‘Views of the person with dementia’2001, *JME*;27:pp86-91

**The Tutorial**

Your sub-groups are shown in the lists on page 11. Each group should have prepared a 5 minute oral summary of their article. Each group should also have prepared a single A4 written summary and brought sufficient copies to distribute to the other members of the group. Tutors will act as facilitators, as far as possible, encouraging the other students to lead the discussion of each article including raising points for clarification.

**Suggested Session Schedule**

5 mins Ice breaking and intro: Students to distribute their one- page summaries. Explanation of aim of tutorial. Nominate time keeper.

3x 15 mins Each group to give 5 minute summary of their article followed by 10 minutes Q+A from rest of group

5 mins Students: please complete the reflective evaluation form for this session (in this guide)

 Tutors: please complete the feedback forms (provided in tutorial rooms)

10 mins General discussion and feedback– How has reading informed/changed perspectives on dementia? Difficulties encountered in preparing for today’s session. Strengths and weaknesses of different groups

**Reflective Evaluation**

Please take 2 minutes to respond to the following questions:

Following the session please upload these reflections on to your ePortfolio on Pebblepad

**1. What have I learnt from today’s tutorial?**

**2. What learning needs have I identified from today’s tutorial?**

**3. How will I address those learning needs?**

## **Session 3 reading**

Margo’s Logo’ A.D. Firlik. 1991, *JAMA*; 256(2):p201

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*Life’s Dominion*. Dworkin R 1993, Vintage Books. New York, Chapter 8, pp218-241
Life Past Reason

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Hughes J. Views of the person with dementia’ 2001, *JME*;27:pp86-91

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*Bioethics an Anthology*, Kuhse and Singer (eds) Part IV,

Chapter 35, pp312-320. R.Dresser ‘Dworkin on dementia: elegant theory, questionable policy‘

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## **Lecture: Ethics in the treatment of children**

**Dr Adrian Raby Glenister Lecture Theatre**

 **1030 - 1130**

**Learning Outcomes**

Following this session you should be able to:

* Discuss the arguments for and against respecting children’s choices
* Identify key factors in determining best interests in children
* Explain a way to consider autonomy interests as part of a broader conception of best interests in children
* Explain how value diversity can lead to differing conceptions of best interests in children
* Discuss when non-therapeutic interventions might be ethically acceptable in children too young to give consent
* Propose a way forward when there is major disagreement between parents, children and health professionals

**Essential Reading**

**Lecture Reading**

‘Consent to Treatment’ in Medical Law and Ethics. J. Hering 3rd ed. 2010, Oxford University Press, Chapter 4, section 15 ‘The ethics of child treatment’ (pp 207-211)

Children tutorial notes – released on Blackboard after today’s session

**Tutorial Reading** (to be completed **before** Friday’s tutorial)

(Articles and weblinks are available on Blackboard under Session 4)

**All groups**

<http://www.ich.ucl.ac.uk/factsheets/families/F040092/index.html>

<http://www.leukaemia.org/about-leukaemia/patient-stories/1011>

Pentz RD, Chan KW, Neumann JL at al. 2004. ‘Designing an ethical policy for bone marrow donation by minors and others lacking capacity’. *Cambridge Quarterly of Healthcare Ethics’* ; 13:149-155

Cwynarski K, Roberts IAG, Iacobelli S van Biezen A, et al. 2003. ‘Stem cell transplantation for chronic myeloid leukemia in children.’ *Blood*;102: 1224-1231, [http://bloodjournal.hematologylibrary.org/cgi/content/full/bloodjournal;102/4/1224](http://bloodjournal.hematologylibrary.org/cgi/content/full/bloodjournal%3B102/4/1224%20)

**Betty Lovejoy: Zeno’s mother**

Delaney L. 1996 ‘Protecting children from forced altruism: the legal approach’. *BMJ*; 312:240 <http://www.bmj.com/cgi/content/full/312/7025/240/a>

Savulescu J. 1996 ‘Substantial harm but substantial benefit’. *BMJ*; 312: 241-242. <http://www.bmj.com/cgi/content/full/312/7025/241>

MacLeod KD, Whitsett SF, Mash EJ, Pelletier MSW. 2003. ‘Pediatric sibling donors of successful and unsuccessful haemopoietic stem cell transplants (HSTC): a qualitative study of their psychosocial experience’. *Journal of Pediatric Psychology*; 28(4):223-231. <http://jpepsy.oxfordjournals.org/cgi/content/full/28/4/223>

**Barney Lovejoy: Zeno’s father**

Month S. 1996 ‘Preventing children from donating may not be in their interests’ *BMJ*; 312:240-241. <http://www.bmj.com/cgi/content/full/312/7025/240/b>

Browett P. 1996. ‘Legal barriers might have catastrophic effects’. *BMJ*;312:242-243. <http://www.bmj.com/cgi/content/full/312/7025/242>

Savulescu J. 1996 ‘Substantial harm but substantial benefit’. *BMJ*; 312: 241-242. <http://www.bmj.com/cgi/content/full/312/7025/241>

**Wilma Mountcastle: Enya’s Mother**

Taylor B. ‘Parental autonomy and consent to treatment’ 1999. *Journal of Advanced Nursing*; 29(3):570-576
<http://www.blackwell-synergy.com/doi/full/10.1046/j.1365-2648.1999.00924.x>

Forinder U et al. 2006 ‘Quality of life following allogeneic stem cell transplantation, comparing parents’ and children’s perspectives’ ; *Pediatric Transplantation;*10:491-496
<http://www.blackwell-synergy.com/doi/full/10.1111/j.1399-3046.2006.00507.x>

**Enya Mountcastle**

[www.anthonynolan.org.uk](http://www.anthonynolan.org.uk)

MacLeod KD, Whitsett SF, Mash EJ, Pelletier MSW. 2003. ‘Pediatric sibling donors of successful and unsuccessful haemopoietic stem cell transplants (HSTC): a qualitative study of their psychosocial experience’. *Journal of Pediatric Psychology*; 28(4):223-231. <http://jpepsy.oxfordjournals.org/cgi/content/full/28/4/223>

**Additional reading**

Pentz RD, Chan KW, Neumann JL at al. 2004. ‘Designing an ethical policy for bone marrow donation by minors and others lacking capacity’. *Cambridge Quarterly of Healthcare Ethics’* ; 13:149-155

**Children- Who decides?**

The child?

The parent(s)?

The health care professional?

***It is helpful to consider two groups of children when thinking about decision making:***

**1.**

**2.**

**Children and autonomous decisions**

***For a decision to be autonomous a child needs to be able to:***

1.

2.

3.

**Children who lack autonomy**

**Babies, infants and younger children**

Decisions made on behalf of children should promote their best interests

**Children and best interests**

***How*** do we decide what is in a child’s best interests?

***Who*** decides what is in a child’s best interests?

**Best interests – who decides?**

What constitutes best interests is a question of value not fact

**Parental Autonomy**

Do parents have a *right* to decide what should be done to their child ?

OR

Do parents have a *responsibility* to do what is best for their child?

**Parental Autonomy- the best interests argument**

1.

2.

3.

***So,***

**Parental Autonomy- the best interests argument objections**

1.

2.

**Parental Autonomy- the parental rights argument**

1.

2.

3.

***Therefore.***

**Parental Autonomy- the parental rights argument**

Problems with the parental autonomy argument:

1.

2.

3.

***Therefore,***

**When parents and doctors disagree**

Generally parents and doctors share the same primary concern: the child’s welfare

However, differing values and beliefs lead to differing assessments of welfare, harm and benefit

Good communication and reflection is likely to improve trust and mutual understanding making it easier to reach an agreed way forward

**Burdensome Treatment**

Can the pain and distress caused by a treatment be worse than inevitable death if treatment is withheld?

Whether a treatment is ‘too burdensome’ is a question of value not fact

**Burdensome Treatment**

Adults can value their lives present and future

Adults can determine the significance to them of the discomfort or pain of treatment

With very young children and babies, parents and doctors will bring their own perspectives in weighing up these values to make decisions

**Quality of life**

* Some argue that quality of life assessments have no place in these decisions
* Life is an intrinsic good
* BUT: this would make it intrinsically good to keep a baby alive even in severe distress
* Others argue that quality of life cannot be measured – no units, vague

**Burdensome treatment**

* “Treatment can be burdensome in two different ways. The treatment itself may be invasive or distressing. Or it can be burdensome by prolonging pain or distress caused by the medical condition. Judgements about either of these kinds of burdensomeness are quality of life judgements. Quality of life assessments should not be abandoned. Certainly, they have a degree of subjectivity. It is true that there are no units of measurement as there are for blood pressure or temperature. But a wise and humane medical practice allows room for quantitative assessment to be supplemented by qualitative human judgement” Jonathon Glover

**OLDER CHILDREN**

**Autonomous children**

Teenagers and older children may meet the criteria for autonomous decision making but may make unwise decisions e.g.

15 year old wanting to continue a pregnancy against her parents advice

15 year old refusing a heart transplant for end stage heart failure

**Problems with children’s choices**

Deciding the weight that should be given to a child’s decision is difficult in part because they are developing physically, cognitively and psychologically

***Thus:***

1.

2.

3.

4.

**Unstable values**

At any one time a child/teenager may have the understanding and value system relevant to the decision being made

***But:***

**Autonomous or not quite?**

Does this provide grounds for overriding what would otherwise be considered autonomous decisions in teenagers or older children?

***What do you think?***

**Children’s rights v paternalism**

Arguments in favour of an autonomous child’s rights to decide:

1.

2.

3.

**Defining Best Interests**

John Eekelaar proposed subdividing children’s best interests into:

1.

2.

3.

**Basic Interests**

Promotion of physical and emotional care and well-being

Ensuring health, security, housing, feeding, clothing

**Developmental Interests**

Promoting development of child as a person:

Education

Socialisation

Confidence

Emotional maturity

**Autonomy Interests**

Promoting development of autonomy

Respecting autonomous choices

**Balancing Interests**

John Eekelaar proposed an approach to balancing the basic, developmental and autonomy interests in children as they grow up:

Basic, developmental and autonomy interests are the interests necessary to ensure current well being ***and*** development into an autonomous adult

Respecting autonomous choices will usually be crucial to this development

***But:***

**If there is a clash between autonomy interests and the other two then:**

***If there is a risk of death or serious harm…***

***As a child matures…***

**Teenage refusal**

S, a 15 year old boy with leukaemia

Devout Jehovah’s witness since the age 9

Accepted autologous bone marrow transplant but refused blood product support

Court ruled that he should receive blood transfusion necessary to save his life

Bone marrow transplant was successful

***Did the Court make the right decision?***

**Non-therapeutic medical interventions in children**

**Best interests and non-therapeutic medical interventions**

Can it be in a young child’s best interests to undergo a non-therapeutic medical procedure?

***e.g.***

1.

2.

**Non-therapeutic medical research**

Inevitably carries some risk

No direct medical benefit

**Non-therapeutic medical research**

Children should be able to participate in non therapeutic research because it allows them to be altruistic

***But…***

1.

2.

**Non-therapeutic medical research**

Children should be able to participate in non-therapeutic research even if it is not in their best interests because:

1.

2.

3.

**Medical Research**

But…

1.

2.

3.

**Summary**

There are potential conflicts between autonomy and best interests. In children it has been suggested that a child’s autonomy interests requires us to ensure that children reach autonomous adulthood

Best interests is a question of value. Mutual respect and good communication is essential if conflict is to be minimised

## **Session 4 Friday 9September 2011**

|  |  |  |
| --- | --- | --- |
| 14:00-15:30 | Tutorial: Bone marrow harvesting debate | G1,G2,G3 Comms A & B |
| 15:30-17:00 | Self directed study: Preparation for session 6 and 7 |  |

**!! Course work to be completed before Tuesday 12th September !!**

Reading for session 6 tutorial (see session 6 reading list)

Prepare and submit group work assignment for session 7

**Tutorial: Bone marrow harvesting debate**

|  |  |  |
| --- | --- | --- |
| **Group** | **Tutors** | **Room** |
| 1 | Dr Adrian Raby  | Glenister seminar room 1 |
| 2 | Dr Kofi Anie | Glenister seminar room 2 |
| 3 | Professor Edwina Brown  | Glenister seminar room 3 |
| 4 | Dr Ana Almaraz | Comms Room A  |
| 5 | Dr Sobana Navaratnarasah | Comms Room B |

**Learning Outcomes**

Following this tutorial you should be able to:

* Discuss the arguments for and against respecting the choices of older children
* Explain how value diversity can lead to differing conceptions of best interests in children
* Discuss when non-therapeutic interventions might be ethically acceptable in children too young to give consent
* Propose a way forward when there is major disagreement between parents, children and health professionals

**The Clinical Ethics Committee**

An increasing number of hospitals have clinical ethics committee. These committees provide a forum for reviewing ethical dilemmas in everyday practice to aid clinical decision making. You have been assigned a role for today’s session according to you tutorial subgroup. As a group you must prepare a witness statement for this role **prior** to today’s session. You will have 15 minutes today to finalise your witness statements.

Your tutor(s) will represent the clinical ethics committee. Each group must defend its assigned position (whether or not they personally agree with it). Today’s session is based on a real life case although the names have been changed. Essential reading (available on Blackboard) has been provided to help you prepare for the session. Tutorial notes for this tutorial will be available on Blackboard following today’s medical ethics and law session.

**Tutorial Schedule**

14:00-14:05 Ice breaking, then vote for or against harvesting bone marrow from Zeno

14:05-10:15 Finalise witness statements

14:15-15:15 Each group presents its statement (5 mins) then cross examined by the ethics committee and then the whole group (10 mins)

15:15-15:30 Students complete 2 minute reflective evaluation form, tutors please complete tutor feedback form

 Tutor Feedback to group

**The Case**

Enya is a 12-year-old girl was diagnosed with chronic myeloid leukaemia 18 months previously when she presented severely ill with sepsis and gum bleeding. She is now in remission following a course of chemotherapy. She is back at school and appears fully recovered. However, her haematologist, Dr R, has explained to Enya and her mother that the remission is only temporary and that within a few years her leukaemia will transform into a much more aggressive form, for which the only possible cure would be a bone marrow transplant. Dr R says that it would be helpful to test all immediate relatives now to look for a suitable bone marrow match. If there is a good match then Dr R advises performing a bone marrow transplant now, whilst Enya is well and in remission. Dr R says that if they wait until Enya relapses the transplant is much riskier and less likely to succeed.

Enya’s parents divorced acrimoniously 5 years ago. Enya’s father remarried 3 years ago and has a 2½ year old son, Zeno. They live a few miles away and Enya sees her half brother every other weekend. Neither of Enya’s parents turn out to be a suitable match. Enya’s older brother, Xatos died 4 years ago following a heart lung transplant for cystic fibrosis, having had multiple hospital admissions and interventions. However, Zeno turns out to be a good match. Zeno’s mother says she Zeno is too young to be a bone marrow donor. Zeno’s father disagrees and thinks they must go ahead with the harvesting and transplant now. Enya says she remembers what her brother went through and that the thought of a transplant frightens her.Enya’s mother says that the treatment for a transplant will make Enya ill again. She has read that the risk of severe Graft versus Host Disease is over 50%. Dr R explains that this can be treated and that there is a70-80% chance that the transplant will cure Enya. Her mother, a devout Christian, believes God’s wisdom should be trusted and is adamant that a bone marrow transplant now is the wrong thing to do.

**Reflective evaluation**

Please take 2 minutes to respond to the following questions:

Following the session upload your notes onto your eportfolio on Pebblepad.

**1. What have I learnt from today’s tutorial?**

**2. What learning needs have I identified from today’s tutorial?**

**3. How will I address those learning needs?**

**Session 5 Monday 12 September 2011**

|  |
| --- |
| Reading for session 6Group work in preparation for session 7Submit presentation for session 7 by midnight 12th September |

## **Session 6 Tuesday 13 September 2011**

|  |  |  |
| --- | --- | --- |
| 09:30-10:30 | Tutorial: Professionalism, cultural diversity and the GMC | G1, G2, G3, R2, R3 |
| 10:45-11:45 | Lecture: ethics at the end of life | GLT |

**!Course work to be completed!**

At the end of the session there will be some time to make final preparations for the group presentation session this afternoon**.**

###

### **Essential Reading**

**Lecture**

‘Dying and Death’ in *Medical Law and Ethics*. J.Herring 2008 3rd Ed., Oxford University Press. Chapter 9: Section 1What is death? (pp462-469), section 4 Ethical issues: euthanasia (pp496-522)

**Tutorial** (to be completed **before** today’s tutorial)

Personal Beliefs and Medical Practice – GMC March 2008

<http://www.gmc-uk.org/guidance/ethical_guidance/personal_beliefs.asp>

(pdf available on Blackboard)

The role of doctors' religious faith and ethnicity in taking ethically controversial decisions during end-of-life care J Med Ethics 2010;36:677

BBC News 26 Aug 2010

‘Religion may alter doctors end of life care’ <http://www.bbc.co.uk/news/health-11083891>

**Additional Reading**

*Bioethics an Anthology*, Kuhse and Singer (eds) Part IV, Chapter 36, pp323-326. C.Hill ‘The note’.

Rachels, J, Actor and Passive Euthanasia in *Killing and Letting Die,* Steinbock, B and Norcross A, 2nd edn ch5 pp112-19.

Daniel Callahan ‘When self determination runs amok’. The Hastings Center Report, vol22, no2, (mar-Apr 1992), pp 52-5

## **Tutorial: Professionalism, cultural diversity**

## **and the GMC**

**Author:** Dr Adrian Raby

**Tutorial time:** 60 minutes

|  |  |  |
| --- | --- | --- |
| **Group** | **Tutors** | **Room** |
| 1 | Dr Adrian Raby  | Glenister seminar room 1 |
| 2 | Professor Terry Cook | Glenister seminar room 2 |
| 3 | Dr Elizabeth Jackson | Glenister seminar room 3 |
| 4 | Dr Andrew Lawson | Comms Room A  |
| 5 | Dr Janet Baldwin | Comms Room B |

**Learning outcomes**

By the end of the session you should be able to:

* Reflect on your own personal beliefs and how these might potentially influence your discussions with patients
* Discuss constructively with colleagues the potential challenges raised by differing personal beliefs
* Appraise professional guidelines
* Apply professional guidelines to practice
* Demonstrate an understanding the role of the GMC
* Reflect on the relationship between ethics, professional guidelines and legal standards

**Introduction**

In this session students use a number of case studies devised by the GMC and a BBC news article about doctor’s decision making in relation to their religious beliefs to explore areas of potential professional difficulty in clinical practice. The role of the facilitator is to guide students though a discussion of the cases and highlight the key issues that arise in the case, along with the sources of information. Students are also encouraged to take a critical view of professional guidance and relate guidance back to key ethical principles that they will have encountered during the course.

**The cases**

There will be IT facilities available in each room, which should allow you to present the GMC in action cases.

To access the cases you have to enter the relevant ‘waiting room’ on the GMC in action page:

<http://www.gmc-uk.org/guidance/case_studies/gmp_module1.asp>

## Waiting Room 1 Katy



## **Scenario 1**

*Katy and Dr Newell*

Katy has come to see Dr Newell because she’s been having panic attacks ever since she “took too many pills two or three weekends ago”. These attacks have stopped her sleeping at night and her health is suffering as a result.

**Katy**: I just lie awake with my heart racing and my breathing getting shallower and shallower. Like I’m going to die. I can’t relax – I’m a million miles from relaxing. I’m terrified that I’m not going to get any sleep and that it’s going to get worse and worse…

**Dr Newell:** Yes it does sound like your having anxiety attacks. They may well have been brought about by taking too many drugs. Katy you really need to think carefully about your lifestyle. If you’re serious about your exams…

**Katy:** Of course I’m serious about them! I’m only doing what every other student my age is doing. Except sleeping that is. Are you going to help me doctor Newell? My sister had panic attacks and she was given some dizie-..diaz…

**Dr Newell:**  Your sister was probably given diazepam, its a tranquiliser, a very addictive drug.

**What should doctor Newell do?**

**Discussion**

This case is designed to highlight difficulties that may occur when doctors have personal values and beliefs that differ from those of their patients. The first scenario can be used to explore the students’ reactions to Katy, and how to respond to her request. The issues of conditions that may be contributed by patients’ lifestyles is also raised.

**Scenario 2**

Katy didn’t attend the follow-up appointment. Two months later Katy comes to the surgery. She has been seeing a counsellor but is still engaging in risky behaviour. She has just discovered that she is pregnant and thinks it could be over three months since her last period. She is distraught and feels there is no way she could cope with a baby in her life and she ‘might do something stupid’. She wants to be referred for a termination as soon as possible.

Dr Newell has a conscientious objection to abortion and does not want to refer Katy, as she feels she would be complicit in the termination if she did.

**Katy:** I don’t know howI let this happen. I hadn’t realised things had got so out of control. I don’t know what I’ll do if my Dad finds out, my life just won’t be worth living!

**Dr Newell:** Calm down Katy. I’ll try and do what I can, but I’m afraid I’m not willing to refer you for a termination myself – it would be against my religious beliefs.

**Katy:** What? I don’t understand, It’s legal isn’t it?? I mean what does that mean?! Dr Newell you have to help me!

**Question. What should the doctor do?**

Critical reading:

You have been asked to read the paper:

The role of doctors' religious faith and ethnicity in taking ethically controversial decisions during end-of-life care J Med Ethics 2010;36:677 Clive Seale

**Possible points for discussion:**

To what extent if any should doctors’ religious beliefs be allowed to influence their clinical practice?

What other examples are there of situations where doctors’ personal or religious beliefs may conflict with clinical practice?

**Reflective Evaluation**

Please take 2 minutes to respond to the following questions:

Following the session upload your reflections onto your ePortfolio on Pebblepad .

**1. What have I learnt from today’s tutorial?**

**2. What learning needs have I identified from today’s tutorial?**

**3. How will I address those learning needs?**

The role of doctors' religious faith and ethnicity in taking ethically controversial decisions during end-of-life care J Med Ethics 2010;36:677 Clive Seale

<http://jme.bmj.com/content/36/11/677.full>

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**Lecture: Ethics at the end of life**

**Dr Adrian Raby Glenister Lecture Theatre**

 **1045–1145**

**Learning Outcomes**

Justify the accepted definition of death

Analyse situations where the withdrawal of life sustaining treatment may be ethically desirable

Understand arguments that draw on the acts/ omissions distinction

Explain different concepts of the Sanctity of Life

Explain the Doctrine of Double Effect and its application to healthcare

Critique arguments used in debates about assisted suicide and euthanasia

**Defining death:**

**The following definitions of death have been or are still used to define death:**

1

2

3

4

5

Pros and cons of some of these definitions are:

The currently medically accepted (Dept of Health) definition of death is:

**Can it ever be in a person’s interests to die?**

We have different types of interests. Dworkin has described

**Experiential interests**. These are:

And

**Critical interests**. These are:

If we look at a person’s ‘critical interests’:

**The term ‘sanctity of human life’ can be taken to have different meanings**:

1

2

**Those who reject the notion of the Sanctity of Human life might use arguments such as:**

The film clip of Richard Rudd demonstrates some of the difficulties in decision making. What does it demonstrate about the difficulties of interpreting patients’ previous wishes?

The case of Anthony Bland:

**Should nasogastric or PEG feeding count as medical treatment?**

Yes:

No:

**Is there a morally relevant distinction between an act and omission that results in death?**

Arguments used against the distinction:

Arguments used in favour of the distinction:

What is the doctrine of double effect?

If an action has a morally bad consequence we are justified in carrying it out as long as the following three conditions are met:

 1

 2

 3

Problems with the doctrine:

The law recognises this distinction in the case of:

**Euthanasia and assisted suicide:**

**Definitions:**

**Euthanasia:**

**Active**

**Passive**

**Voluntary**

**Non voluntary**

**Involuntary**

**The legal position in the UK is:**

**Arguments used in favour of legalising assisted suicide include:**

**Autonomy:**

**But:**

**Dignity:**

**But:**

**Arguments against:**

**Sanctity of life:**

**But:**

**Slippery slope arguments:**

**But:**

Killing and Letting Die. Steinbock B and Norcross A. 2nd Edn Ch 5 pp112-119

Rachels J, ‘*Active and Passive Euthanasia’*

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 *Bioethics an Anthology*, Kuhse and Singer (eds) Part IV,

* Chapter 37, pp327-331. D.Callahan ‘When self determination runs amok’.

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* Chapter 36, pp323-326. C.Hill ‘The note’

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## **Session 7 Tuesday 13 September 2011**

|  |  |
| --- | --- |
| 14:00-15:00 | Tutorial: Group presentations  |
| 15:15-16:00 | Lecture: resource allocation, healthcare and justice |
| 16:00-16:30 | Lecture: Constructing ethical arguments and preparing for the exam |

**Tutorial: Group presentations**

|  |  |  |
| --- | --- | --- |
| **Group** | **Tutors** | **Room** |
| 1 | Dr Adrian Raby  | Glenister seminar room 1 |
| 2 | Professor Terry Cook  | Glenister seminar room 2 |
| 3 | Dr Elizabeth Jackson and Dr Ginny Wright | Glenister seminar room 3 |
| 4 | Dr Andrew Lawson and Dr Ana Almaraz | Comms Room A  |
| 5 | Dr Janet Baldwin | Comms Room B |

You will work in your groups to prepare and deliver your PBL group assignment. You must prepare your presentation BEFORE the session on 13 September.

Only your PBL group lead can submit the presentation. If your group wishes to request a different group lead you must inform Dr Adrian Raby by email (a.raby@imperial.ac.uk) no later than ***0900 on Friday 9 September***

**Learning outcomes**

Following this session you should be able to:

* Explain the key ethical arguments around resource allocation including ageism, social worth and personal responsibility in resource allocation decisions
* Outline different ways of choosing which medical conditions to treat
* Discuss the relationship between justice and healthcare in resource allocation decisions
* Reflect and respond to feedback on your ethical arguments
* Listen and respond constructively to the ethical arguments of your colleagues

**Essential reading**

‘The Structure of the NHS’ in *Medical Law and Ethics*. J.Herring 3rd ed. 2010, Oxford University Press. Chapter 2: Section 9.5-9.6 ‘How should healthcare be rationed?’ and ‘Controversies over rationing’ (pp 75-87)

**Additional reading**

Resource allocation e-module – to be released on Blackboard

## **Group PBL assignment**

**!Formative assessment!**

This group assignment is your formative assessment for this course.
The deadline for submission via Blackboard is midnight on Monday 12th September

Your PBL group lead (appendix 1) must submit your PBL presentation via Blackboard if you wish to be signed off for this course

After the session you **must** log on to WebPA (see below) and rate your peers

**Aims**

The aims of the presentation are:

1. To develop your skills in ethical and legal reasoning.
2. To develop your ethical and legal analysis through group discussion.
3. To learn how to present your ethical and legal arguments in a clear and persuasive manner.
4. To learn how to use ethical and legal analysis in clinical decision making.
5. To critically reflect on group work, including your own role and that of others within the team.

**Each presentation should last no longer than 10 minutes. This will be followed by 10 minutes of Q+A.** Your mark sheets will be returned at the end of the session. You will be marked according to your presentation, your ethical analysis and your performance in the Q+A session.

PBL group leads must bring a mark sheet with their group’s name (eg 1C) **and** the names of the individual group members to the tutorial. You can find the marking sheet on Blackboard. The assessment and feedback sheet below gives you guidance as to what we will be looking for in your presentation.

**Your presentation should address:**

1. An outline of the case, defining the relevant medical indications and ethical issues
2. Patient factors including preferences and quality of life where relevant
3. A **range** of ethical arguments that have been proposed for rationing decisions that are **relevant to the specific case**
4. The strengths and weaknesses of these arguments
5. Weighing up and balancing the relevant arguments
6. Formulating a conclusion

The presentation should cover a case or issue that has been presented in the media in recent months or years, where a key theme in the case is the allocation of health care resources. The presentation should outline the case, the relevant ethical considerations, and present arguments as to how any ethical dilemmas might be resolved. There will be three groups presenting in your allocated session. You will need to ensure that each group within a particular session chooses a different case or topic.

Recent examples include:

‘Mum denied cancer drug funding has to sell her house’

<http://www.dailymail.co.uk/news/article-464101/Mum-denied-cancer-drug-funding-sell-house.html>

NICE rejects lapatinib for advanced breast cancer

<http://info.cancerresearchuk.org/news/archive/cancernews/2010-06-09-NICE-rejects-lapatinib-for-advanced-breast-cancer>

Obese patients denied operations

<http://news.bbc.co.uk/1/hi/england/suffolk/4462310.stm>

Q&A: US healthcare reform

<http://news.bbc.co.uk/1/hi/8160058.stm>

NHS cancer drug fund available 'as soon as possible'

<http://www.nursingtimes.net/whats-new-in-nursing/acute-care/nhs-cancer-drug-fund-available-as-soon-as-possible/5016048.article>

**Teamwork assessment**

The individual mark that you will receive for this assignment will be derived from the tutor’s assessment of the group presentation, moderated by your peers’ assessment of your own contribution to the exercise. The group will receive a mark out of 100, which will then be weighted according to your peers’ assessment of your contribution, with 20 per cent of the mark being peer assessed.

Following the presentation you will need to log on to WebPA using your college username and password. The link to the website is:

<https://www2.imperial.ac.uk/peerassessment/webpa/login.php>

You will have to have entered your scores by midnight of Friday 16th September 2011. Failure to submit a peer score will result in a penalty of 5 percentage points from your individual score.

In rating your peers you will be asked to split 100 marks between the others in the group, according to your assessment of their relative contribution to the exercise. In doing so you are asked to be as objective as possible. In order to ensure fairness, where you have opted to allocate less than 10% of the marks to an individual you are asked to justify this with written comments. Please bear in mind that, whilst group members will receive anonymous feedback, these marks and comments are attributable to you, and will be viewed by the course leader and group tutors. You should therefore follow the rules of feedback that have been emphasised earlier in the course, and ensure that any criticism is framed constructively.

## **Group PBL Presentation Assessment Form**

Group members: Group No. **...........**

Title: **.............................................................................**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | BelowExpectations**0** | Borderline**1** | MeetsExpectations**2** | AboveExpectations**3** |
| **1. Identifying a suitable case**The case that was chosen allowed arguments relating to resource allocation to be explored  |  |  |  |  |
| **2. Medical context of case**There was clear understanding of the impact of the condition on those affected or on society as a whole |  |  |  |  |
| **3. Identification of ethical arguments**The group identified different perspectives as to how the resource allocation problem should be resolved  |  |  |  |  |
| **4. Balancing of arguments**The persuasiveness of different arguments was considered in relation to the case. The reasons for accepting or rejecting arguments was made clear |  |  |  |  |
| **5. Conclusion**The group made their choice based on a logical and robustly defended conclusion of their ethical analysis  |  |  |  |  |
| **6. Clarity and style of presentation**The presentation was clear and easy to follow and was engaging and interesting |  |  |  |  |
| **7. Group participation**The group has listened and reflected on the views of their peersThe group has responded coherently to questionsThe group has worked effective together in writing and giving this presentation |  |  |  |  |
| **TOTAL MARK (/21)** |  |

|  |  |
| --- | --- |
| **Particular Strengths** | **Suggestions for development** |
|  |  |

Tutor Name .........................................................................................................

(please print and sign)

**Assessment Guidance**

Groups will be assessed on both their presentation and discussion. The assessment sheet has 7 domains. Within each domain guidance is provided, showing the areas that we expect students to cover. Use the full range of the rating scale.

1. *Identification of a suitable case.* Students should have identified a real-life case covered in the media in recent months or years that raises resource allocation issues.
2. *Holistic medical context of the case.* Students are expected to demonstrate an understanding of the medical, personal and social context of the case, identifying those features that are relevant to the ethical analysis. This should include demonstrating familiarity with relevant empirical evidence. A ‘meets expectations’ group would provide a succinct overview of the key medical, psychosocial, societal aspects of the condition relevant to ethical argument including some empirical evidence to support their overview.
3. *Identification of Ethical arguments*: Students are expected to demonstrate that they identified a range of ethical approaches relevant to the analysis of their case. A meets expectations group should have identified and succinctly described at least 2 ethical approaches and explained how these approaches would be applied to their specific case
4. *Balancing of arguments:* In their presentation should reflect on the ethical arguments/approaches that they have identified, discussing the strengths and weaknesses of the different approaches. A ‘meets expectations’ group would provide a persuasive and coherent discussion of the strengths and weaknesses which follows a logical progression.
5. *Conclusion:* The group is expected to present a conclusion that follows logically from their ethical argument and reflection. There should therefore be a robust defence of their final decision and clear argument as to why the counter arguments were unsatisfactory. A ‘meets expectations group would be one that presented a clear and persuasive conclusion that addressed the resource allocation dilemma and followed logically from their ethical analysis. A borderline group would be one with conclusion that showed ethical reasoning but that did not follow on from the rest of their presentation. A group that was below expectations would be one that ended with their personal opinion and no attempt to defend their position.
6. *Clarity and style*: Students should be assessed on their slides and their accompanying oral presentation. A ‘meets expectations’ group would be one that engaged the audience throughout most of the presentation with clear arguments and explanations that required little clarification and kept to time.
7. *Discussion and group participation:* The Q+A session provides an opportunity for the tutor to get clarification on arguments put forward in the presentation and to encourage the students to reflect more deeply on their position. The group is expected to demonstrate a clear understanding of the arguments and counter arguments that they have put forward in their presentations and to be able to reflect on and defend their position in response to questioning. The overall performance of the group during the presentation and discussion is expected to demonstrate that the students have worked together as a team on the assignment and in the Q+A. A borderline group would be one that one that had difficulties defending their position when questioned or where it appeared that not all the members had made a substantial contribution to the assignment

## **Lecture: Resource Allocation**

**Dr Adrian Raby Glenister Lecture Theatre 1515 – 1600**

**Learning Outcomes**

Understand what is meant by the term Justice when used in ethical arguments

Consider whether access to healthcare is a matter for Justice

Consider the merits of different approaches to distributing limited health care resources

Understand QUALYs and their application by NIHCE

**Is healthcare special?**

The provision of many if not most goods in society are determined by market forces. Few would argue that the provision of iPads requires any particular state intervention. Whether someone owns an iPad simply depends on whether he or has sufficient money to buy one, and if so it is a matter of personal choice.

Many argue that healthcare is special however and therefore its availability requires the application of Justice.

**Different Notions of Justice**

Justice encompasses the notion that within a society there should be equality of

treatment where people deserve the same treatment, but that people may be

treated unequally in proportion to their relative deserts.

**Different concepts of justice include:**

1.Libertarian

2.Utilitarian

3.Marxist

4 Rawles

**Rawles 2 principles:**

**1 Liberty Principle. States:**

**2 Equality Principle. States:**

**Healthcare can be seen as a basic human need, because:**

* **Meeting healthcare needs helps us maintain normal functioning**
* **Normal functioning has a major impact on our opportunities in society**
* **Opportunities in society are a matter for Justice**

**THEREFORE**

**….**

* + **FURTHERMORE**
* **Justice requires equality in opportunity**
	+ **SO**

**….**

**Problems:**

**1 What counts as healthcare?**

 **Acute care:**

**BUT**

**Mental health:**

**BUT**

**Prevention and screening**

**BUT**

**Where are the limits?**

**Adequate nutrition, shelter? Sanitation and unpolluted living and working conditions? Exercise, rest?**

**Problem 2**

**To what should there be equitable access.**

Even if we have demonstrated that the provision of healthcare is a matter for Justice, to what should we have access. ? a basic minimum ? comprehensive healthcare?

**Different ways for distributing resources ‘fairly’:**

 **Need**

 **Merit**

 **Social worth**

 **Lifestyle**

 **Age**

 **Dependants**

 **Utility**

 **Lottery**

**Merit**

**Social Worth**

In Seattle in 1962 a renal unit used social worth to determine who should receive dialysis

Problems with this approach include:

 1

 2

 3

 4

 5

 **Age**

**Arguments for using age as a factor in allocating resources**

* **‘**Fair innings’ arguments (Williams 1997)
	+ Would we prefer money spent on us (when ill) when we are young or when old?
	+ Everyone should have an equal chance of reaching a certain age
	+ After that age any extra life is a ‘bonus’

**Arguments against:**

**1**

**2**

**3**

**4**

**5**

**6**

**Lifestyle**

* 1/3 of all disease attributable to lifestyle factors e.g
	+ Obesity
	+ Smoking
	+ Alcohol

**Objections**

* Who is to blame for what?
* Complex social factors
* Risky sports?
* Risky occupations – fire fighters?

Therefore a legitimate consideration only when:

…

 **Dependents**

Arguments for:

Arguments against:

**Utility**

* Greatest benefit for the greatest number
* What do we mean by benefit?
* Whose benefit – individual or society ‘as a whole’

**QUALYs**

* Quality Adjusted Life Year
* Used by NICE
* 1 year of full quality life = 1 QUALY
* 1 year of less than perfect health <1
* Death = 0
* [NICE](file:///C%3A%5CUsers%5Cadrian%5CDocuments%5Cethics%5Cpapers%5CResource%20allocation%5CArticle%20from%20Telegraph%202009.pdf) – if the QUALY value >£25,000-£30,000 need to be special reasons to regard as cost effective
* Cervical cancer screening £200
* Breast cancer screening £6,800
* Coronary artery bypass £26,000
* Dialysis end stage renal dis £45,000
	+ - * Hope, Savulescu, Hendrick 2003

**Problems:**

**1**

**2**

**3**

**4 Ignores our preference for individual lives over life years**

**5 John Harris argues:**

**6**

**Perhaps a solution is to canvas public opinion:**

**Experience of this in Oregon USA**

* **Oregon Basic Health Services Act 1989**
	+ **Citizens ranked treatments in order of worth**
	+ **Public funding available for 587/709 treatments on the list**
	+ **Treatments or thumb sucking rated higher than ectopic pregnancy or AIDS**
	+ **Problems – incapacitating hernias still not funded**

**SUMMARY:**

* **Health is of special moral significance**
* **The provision of healthcare is a matter for Justice**
* **Different approaches to the allocation of resources have been used**
* **Using ethical analysis leads us to conclude that some methods are fairer than others**
* **To decide which is the fairest requires the application of a theory of Justice**

## **Lecture: Constructing ethical arguments and preparing for the exam**

**Dr Adrian Raby Glenister Lecture Theatre**

 **1600 – 1630**

**Aims of the course**

To recognise ethical issues in everyday clinical practice

To develop skills in ethical analysis and reasoning

To understand your professional responsibilities in medical practice

To critically appraise the law

To use these skills to become better doctors

**Mrs M**

Mrs M is 78 years old. She is partially sighted due to macular degeneration, she has severe renal impairment (her eGFR is 6) due to her poorly controlled hypertension. Her renal function is steadily declining. She requires dialysis.

**Mrs M** **– the facts**

Mrs M is **78 years old**. She is **partially sighted** **due to macular degeneration**, she has **severe renal impairment (her eGFR is 6)** due to her **poorly controlled hypertension**. Her **renal function is steadily declining**. She requires dialysis.

**Mrs M – value judgement**

Mrs M is 78 years old. She is partially sighted due to macular degeneration, she has severe renal impairment (her eGFR is 6) due to her poorly controlled hypertension. Her renal function is steadily declining. **She requires dialysis**.

**Mrs M**

Good ethical decision making depends on good clinical knowledge, good communication skills and good information.

What information is missing?

**Mrs M**

Clinical facts:

Stage 5 kidney disease

Prognosis – evidence?

Dialysis – 4 hours 3 times a week

Mrs M

Mrs M’s husband died from Alzheimer's disease 3 years ago

She lives alone

No children

Previously enjoyed art and French literature

Appalled by the prospect of being dependant on others

Is strongly opposed to the prospect of dialysis

**Ethical issues**

Patient preferences, autonomy and choice

Dignity

Quality of life

Physician autonomy

**Ethical reasoning**

Recognising values core to ethical reasoning

Critically analysing values

Using analysis to make better decisions

Using analysis to critically appraise the law and professional guidance

**Ethical reasoning should be:**

Coherent

Consistent

Based on good factual information

Impartial where there is no ethically relevant difference

Clear

**Coherent**

‘Patients have the right to refuse dialysis but my role is to try to persuade them to agree as it is in their best interests’

**Consistent**

‘The NHS should not pay for treatment for self inflicted problems due to lifestyle choices and therefore smoking, alcohol or drug related illnesses.’

‘Obviously the NHS should pay for the treatment of injuries such as fractures caused by playing sports’

**Impartial**

I don’t smoke

I don’t think the NHS should treat smokers

**Based on good factual information**

**Clear**

**Ethical theory**

Ethical theory can provide a framework for approaching and analysing ethical dilemmas

Ethical theory does not provide an algorithm which will give you ‘the answer’

An understanding ethical theory can help you clarify your thinking around an ethical dilemma

**Consequentialism and utilitarianism**

An action is ethically right if it brings about the best foreseeable consequences.

Utilitarianism is a form of consequentialism which states that the right action is that that brings about the maximum overall happiness

A democratic approach – equal weight given to each individual when calculating overall happiness

**But…**

May be difficult to predict consequences

The only ethically relevant feature of an action is its consequences. Thus in certain situations lying, killing, torture may be the ethically right thing to do

Under a consequentialist approach we are as morally responsible for our omissions as we are for our actions if the net result is the same

Utilitarianism is not concerned with ensuring a fair distribution of social goods

There are morally valuable factors other than consequences

**Duty based theories**

According to duty based (deontological) theories certain actions are right or wrong in themselves irrespective of the consequences.

e.g. a duty not to kill, a duty not to torture, a duty to keep promises

Simple - does not require prediction or calculation of consequences of an action

**But…**

How do we decide which actions are right and which are wrong?

What do we do if our moral duties conflict?

Absolves the individual from any moral responsibility for the consequences of their actions even if the consequences are very bad

**Principalism**

**Beneficence**

**Non-maleficence**

**Respect for autonomy**

**Justice**

**Virtue ethics**

A virtue is a character trait a human being needs to flourish or live well

Aristotle (4th C BC)

The best life of a human being consists in the exercise of the virtues e.g. honesty, integrity, wisdom, courage, fairness, compassion

Virtues can be nurtured and developed

The right course of action is the course that a virtuous individual would take

The reason that I should not lie is not that it is wrong or that it has a bad effect, but because it is *dishonest*

**A Feminist approach**

Ethical dilemmas occur in real time with real individuals. Attempts to abstract the ‘morally relevant factors’ oversimplifies the dilemma and ignores morally important relationships

The process by which an ethical dilemma is resolved is as morally relevant as the final decision. Thus facilitating discussion of all interested parties, listening and reflecting on differing perspectives, negotiation and reaching consensus are central to ethical decision making

**FOCP Exam Format**

* Open book exam
* 75 minutes Modified Essay Question

70 marks

Questions will cover:

Ethics – 30 marks,

Clinical communication – 20 marks

PPD – 20 marks

* A past paper is available on Blackboard in the Medical Ethics area under Assignments, assessments and exams

**General exam technique**

* Read the questions
* Answer the questions NOT what you think the questions should be!
* Allow one minute per mark and stick to this.
* Your writing must be legible
* Plan your answers
* Generally 1 or 2 well constructed arguments with well constructed counter arguments and a logical conclusion will gain full marks

**The Modified Essay Question**

* The scenario with references will be released 4 weeks before the exam
* In the exam you will be presented with the same scenario but with a series of questions interspersed into the scenario.

**Open Book Exam**

* No text books, 20 sides of printed/handwritten material including references
* You will not have time to do your reading in the exam
* You will not have time to work out detailed arguments from scratch
* So you must have thought through and prepared your arguments before the exam
* Make good notes that you can navigate through in the exam

**The Modified Essay Question: preparation**

* Read the scenario
* Identify the ethical, communication and PPD issues
* Read the references and course work
* Consider the issues, reflect on the evidence and relevant arguments
* Consider how the theory applies to this case
* For ethics - establish YOUR position based on your reflection andanalysis

**The background material**

* It allows you to question spot
* Eg : A series of papers regarding the ethical dilemmas around terminal care of the elderly
* Usually means ethical dilemmas in assisted reproduction will be saved for the September club.
* It is supporting evidence not replacing your arguments

**Planning essays**

* Highlight key words - focus on what asked
* Plan – 5 minutes – brainstorm main arguments for and against
* No waffle/concise
* Logical point by point development
* Clear arguments and counter-arguments
* Not just own views
* Timing – 1 mark/minute

**Structure of essay**

* Introduction
* Body of essay
* Conclusion

**Introduction**

* Show understand question – define terms
* Use key words from question
* Approach you will take: “I will consider the arguments for and against....”
* Get to grips with topic – something specific

**Body of essay**

* One argument/point per paragraph
* Structure each paragraph
	+ First sentence – make proposition
	+ Develop argument – expand on point
	+ Add evidence/illustration to back up

**Body of essay – next point**

* Use linking words to follow on from previous point
	+ “Whilst it can be argued ...., it is also true that ....”
	+ “However, to counter this argument ...”
* Alternate for and against OR
* Give all “for” arguments, then all “against”
* Develop each argument as before

**Constructing an ethical analysis – a suggested format**

* First paragraph - make proposition
* Develop arguments justifying proposition
* Add evidence (where applicable) to support argument
* Second paragraph – counter argument/weaknesses of 1st proposition
* Third paragraph – alternative proposition that addresses that weaknesses you have identified
* Conclusion

**Reaching a conclusion**

* Your conclusion needs to be consistent with your preceding analysis
* Reflect on the arguments and counter arguments
* Identify which viewpoint, on the basis of your prior analysis, you consider to have greater validity

**Using empirical evidence**

* Reflect on your position and your arguments in the light of available empirical evidence
* Use the empirical evidence to support your ethical arguments NOT replace them

**References**

* Use of references without explanation will not gain marks
* Well constructed without references can gain full marks
* Appropriate use of references that demonstrates your understanding and reasoning may help you gain marks while with fewer words
* Reading and reflecting on the arguments of others is a core part of your ethics teaching
* If you quote or paraphrase another person’s argument, reasoning you must acknowledge this

**Who fails?**

* Candidate who doesn't put *something* for each of the questions.
* Candidate who spends too much time on one answer and leaves no time for another
* If asked for ethical arguments then give ***ethical*** arguments

**Summary – Ethical reasoning**

Good medical practice requires ethical decision making

It is essential to recognise when value judgements are being made

Sound ethical reasoning is key to assessing value judgements

An understanding of ethical theory can help bring clarity and consistency to your ethical reasoning

**Summary – Exam**

* Understand question – define terms
* Plan – points and timing
* One point per paragraph
* Back up points e.g. illustrations/examples
* Sum up to concluding emphasis
* Good luck!

## **Appendix 1: Guide to Tutorial Rooms**

**Glenister Lecture Theatre (GLT) and seminar rooms (G1, G2, G3):**

The Glenister building is on the left as you exit the cemetery. The three seminar rooms are on the ground floor; the entrance to the lecture theatre is on the first floor.

For all other rooms at the campus, cross Margravine Road and go up the steps. into the Reynolds Building on the right.

**Reynolds Building: enter the building through the second set of glass doors**

**R1, R2 & R3:** go up to the first floor of the Reynolds Building.

**R1:** turn left at the top of the stairs, go through the swing doors and turn left.

**R2:** directly ahead of the top of the stairs.

**R3:** turn left at the top of the stairs, go through the swing doors and follow the signs to the Faculty of Education Office (Medicine), R3 is on the right before you reach the student counter.

**Communication rooms A, B, C, D:** go up to the first floor of the Reynolds Building, to through the doors on your left, turn right and the rooms are on your left in the corridor ahead of you.

**PBL1:** go to the 2nd floor of the Reynolds Building into the library and walk straight ahead through the library turnstiles (using your ID card).