End of Life Issues in Islam and Judaism  
A Pilot one-day educational programme

Final Report for the Islamic Studies Network
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Contents

Part 1

Background p. 3
Centre for Public Education, vision, mission statement and methodology p. 3
Aims of the end of life project p. 4
Initial scoping conversations p. 5
Research and preparation p. 6

Part 2

Questionnaires and evaluation p. 9
Pre-course questionnaire p. 9
Course delivery p. 10
Immediate post-course questionnaire p. 11
Three-month follow-up questionnaire p. 12
Conclusions p. 14

Appendices

1. Course timetable and panel members p. 18
2. Course leaflet p. 20
3. Pre-course questionnaire (full) p. 23
4. Immediate post-course questionnaire (full) p. 40
5. Three-month follow-up questionnaire (full) p. 46

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Part One

Background

The Woolf Institute is dedicated to studying relations between Jews, Christians and Muslims. It consists of The Centre for the Study of Jewish-Christian Relations (CJCR), The Centre for the Study of Muslim-Jewish Relations (CMJR) and The Centre for Public Education (CPE).

The need for a course relating to end of life issues embedded within an actual health-care context became apparent during a Woolf Institute research project undertaken during 2009/2010 by an anthropologist of religion and CMJR Research Fellow, Dr Marta Dominguez Diaz, which examined religious variations in attitudes towards death, dying and grief among Muslims and Jews in Britain. Her project resulted in a one-day conference entitled ‘Life and Death in Judaism and Islam’ which took place on 26th May 2010, St Edmund’s College, Cambridge organised by the Centre for the Study of Muslim-Jewish Relations (CMJR) and the Prince Alwaleed Bin Talal Centre of Islamic Studies (CIS). It consisted of four sessions: Medical practice at the end-of-life in Judaism and Islam, Academic approaches to life and death in Judaism and Islam, Religious Insights into Life and Death, End-of-life Issues and Chaplaincy.1

The initial proposal and funding application to the Islamic Studies Network was made by Dr Diaz. However, immediately following the application Dr Diaz went on maternity leave and the project was transferred to the Woolf Institute’s Centre for Public Education led by Dr Claire Henderson Davis. The other team members for the project were Trisha Kessler, Alice Thompson and Andrew Brown.

Centre for Public Education (CPE): vision, mission statement and methodology

Vision:

The vision statement of the CPE is a society in which individuals and communities from particular religious traditions are able to participate in the public sphere, using their wisdom, knowledge and experience for the public good. Furthermore, it is a society in which the values of diversity and tolerance, enshrined in the idea of the public sphere, are embraced and articulated within particular religious traditions themselves.

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Mission Statement:

CPE works by creating partnerships with public sector bodies such as the NHS, the police and local government, and increasingly with the private sector in the form of business, which facilitate the encounter between different religions and between religion and society. We focus on specific areas of interface, grounding our work in particular social and professional contexts, in the lived experience of real people and communities. This approach allows us to remain faithful to the tremendous diversity of religious beliefs and practices both within as well as between different religious traditions.

Supported by the research and expertise of the two academic centres at the Woolf Institute, the Centre for the Study of Jewish-Christian Relations (CJCR), and the Centre for the Study of Jewish-Muslim Relations (CMJR), CPE develops practice-based, context specific projects using this wealth of institutional knowledge about relations between Judaism, Christianity and Islam as the basis for teaching more widely applicable skills of engagement and encounter.

Methodology

CPE employs a methodology that is practiced-based, context specific and process driven. We develop programmes as a result of external requests, in relation to internally-generated research or in response to public policy. Our projects are formulated through a process of careful consultation with all relevant parties, resulting in a programme agreed by all. The gathering of case studies is a key part of our method because it grounds all conversation and analysis in the lived experience of participants. Because human relationships are at the heart of our work, there is always an element of the unknown and the unexpected built into our projects – space to see what happens when people start to talk, and the flexibility to incorporate these ‘as it happens’ developments into our work without loosing focus. This combination of rigorous planning, research and responsive spontaneity gives our approach an entrepreneurial flavour that distinguishes it from more mainstream methodologies.

Aims of the end of life project

The initial aim of the project was to develop a cross-disciplinary educational programme tailored to healthcare providers (including doctors, nurses, medical students and chaplains), those in higher education (particularly in the fields of Islamic and Jewish studies) and also members of the wider academic community who are dealing with the end of life issues. The programme was to be delivered through a one-day course to be piloted in an academic/healthcare with the aim of improving participants’ understanding of:

- the role played by religion in medical performance.
- how Islam and Judaism can contribute positively to a wider societal debate on how to provide appropriate healthcare to an increasingly diverse population.
• the extent to which Muslim and Jewish patients rely upon their religious beliefs to cope with illness and death.
• how end of life issues play out differently in different contexts and situations, i.e. hospitals, hospices, care homes and in patient’s own homes.
• the difference between theological and non-religious secular understandings of death, ownership of the body, informed consent, pregnancy and termination, conscientious objection and other language issues.
• the care of Muslim and Jewish patients and their families around such issues as gender etiquette, moment of death, post-mortem issues, death-certification and release of body and burial.

Initial scoping conversations

Using the Woolf Institute’s existing contacts and a number of preliminary site visits we identified that the most appropriate place to trial such a course would be the Marie-Curie Hospice in Hampstead in collaboration with the Royal Free Hospital.

It is important to state that, from the outset that the generosity and openness of both institutions’ chaplaincy teams and medical staff directly involved in palliative care enabled us to have a number of vitally important scoping conversations at the beginning of the course development process. As will have been seen from the methodology followed by the CPE team this approach is central and helped us both to fine tune the course aims and then to fulfil them in a way that was directly relevant to actual health-care settings and needs. Through this conversational process we gained some initial key insights outlined below which directly influenced the final shape of the course.

It may seem a cliché to observe that doctors and nurses are very busy people but, because they are required continually to attend Continuing Professional Development (CPD) courses to ensure their knowledge is up to date, this means they will only attend those courses which they feel will genuinely help them continue to deliver effective medical care.

At an initial meeting with the palliative care team and the Chaplain at the Marie Curie Centre it quickly became clear that, although it was not that a one-day course concerning religious issues at end-of-life was perceived by them to be uninteresting or unimportant (in fact the medical staff we talked all acknowledged the importance of religion and spirituality in end of life situations and were attempting to ensure that both Department of Health’s 2008 End of Life Care Strategy and the General Medical Council’s guidelines on this matter were followed) rather, that there existed a strong perception that any one-day course would not be able to achieve this in a way that would have a meaningful, direct and immediate effect upon their professional ability to provide appropriate healthcare. There was a strong perception that such a course would involve learning in a passive way a great deal of technical, complex and often highly abstract information about religion that would be of little immediate

relevance to their situation. It was made clear to us that very few staff would feel able to take time out of their very busy schedules to attend such a course. These responses opened up the space to begin a deeper conversation with the staff about what they felt would be of practical use to them in this aspect of their work and through it a number of things were clarified. In order to proceed effectively we had to:

1) be clear that we would be working from actual case studies in which religion had impacted (in any way) upon their ability to deliver effective end of life care. Unless the course could be seen to be rooted in actual medical settings it would not provide what the staff felt was needed.

2) ensure that in the delivery of the course, in addition to the Woolf Institute’s academic staff's research and teaching input concerning Islamic and Jewish issues, there had to be fully involved a panel of experienced doctors, nurses and chaplains to ensure that the case studies could be talked through in both authentic and genuinely helpful, practical ways.

3) make it clear why it was not necessary to know everything about a patient's religion/spirituality in order to begin to engage conversationally with them in effective and helpful ways – ways that both enhanced the patient’s overall feeling of well-being and which enabled doctors to provide treatment that was sensitive to, and took appropriate account of the patient’s religious worldview. The immediate background to this need is that the General Medical Council’s current guidelines on discussing end of life care with patients states that such a discussion should include ‘the feelings, beliefs or values that may be influencing the patient's preferences and decisions.’

4) ensure that the course offered CPD (Continuing Professional Development) credits from an appropriate professional body – in this case the Royal College of Physicians.

**Research and preparation**

Having identified these fundamental issues the five parallel areas of research/preparation we then pursued were the:

1) research, collation and summarisation of key normative Islamic/Jewish theological positions in relationship to end of life situations and key biomedical issues.

2) research, collation and summarisation of key normative medical positions in relationship to end of life situations and situations and key biomedical issues

3) recruitment of a team of panellists consisting of doctors, nurses and chaplains.

4) collection of case studies from this team and also, where possible, from prospective course participants.

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5) Application for CPD credits, publicising the course and organising general practical arrangements for the day (room, refreshments, lunch, public address system, the filming etc.)

The Woolf Institute team was aware from the outset that what exactly the appropriate, effective, final shape of the one day course would be like would only become clear insofar as we were able to create a space in which the relationships between all the panel members and the issues they were addressing could play out naturally and this shape was allowed to emerge. In consequence once the panel members had been recruited, we continued to talk with them both individually and, on two further occasions, with all of them together to talk and walk through, as well as finalise, the content and structure of the day.

The expert panel that we recruited consisted of Mr Mahmoud Al-Akraa (Consultant Urological Surgeon); Imam Rashid Ayyub (Muslim Chaplain, the Royal Free Hospital); Rabbi Bernd Koschland (Jewish Chaplain, the Royal Free Hospital); Rabbi Markus Lange (Resident Chaplain, Marie Curie Hospice, Hampstead); Dr Philip Lodge (Consultant in Palliative Medicine, the Royal Free Hampstead NHS Trust, Marie Curie Hospice, Hampstead); Elizabeth Thomas (Clinical Nurse Specialist); Dr Adrian Tookman (Consultant Physician in Palliative Medicine, the Royal Free Hampstead NHS Trust, Medical Director, Marie Curie Hospice, Hampstead).

Unfortunately, due to illness, Imam Rashid Ayyub had to withdraw one week before the course was held but we were fortunate to have suggested as a replacement Imam Ahmad Faruq (Muslim Chaplain, Barts & the London Hospital). Important mention should also be made of Revd Robert Mitchell (Lead Chaplain, Royal Free Hospital) who, although he could not take part in the actual event due to prior commitments, was a key facilitator of our initial conversations as well as an important contributing voice during the preparation of the course.

As conversations with this team unfolded and we collected together their case studies the following areas of concern begin clearly to emerge:

- Withholding & withdrawing treatment, hydration & nutrition
- Gender issues
- Resuscitation
- Language
- Death certification
- Definitions of death
- Religious practices at the end of life
- Cultural/religious issues
- Tissue samples for research
- Suicide
- Role of Chaplains
- Post-mortem examinations

The one area we felt was of general importance but which did not generate a case study was that of organ donation.
The subjects that we were to cover and the basic structure for the day that began to emerge from our conversations was as follows:

1) A general, opening session in which Woolf Institute tutors would, firstly, situate the course firmly within the context of current NHS and GMC guidelines and the wider context contemporary society and secondly, introduce the key normative sources of authority in Islam and Judaism as well as their basic principles of decision making in matters concerning end of life.

2) Three subject areas in turn with, for each of them, a general introduction followed by a related case study/studies which were firstly to be spoken to by the panel members and then opened up to the floor for further questions/contributions. The subjects we finally settled on were: a) the role of chaplains, b) withholding & withdrawing treatment, hydration & nutrition, c) definition of death.

3) A break followed by small group sessions in which participants were led by a panel member through a case study from one of the three subject areas just covered.

4) An open plenary session with feedback from the small groups and questions and comments from the floor on the three subject areas just covered.

5) Lunch

6) An afternoon session in which three further subject areas were covered (as in section 2 above) and which was concluded by some general summaries of subjects it was not possible to explore fully during the day. The subjects we finally settled on were: a) cultural verses religious issues, b) specific Muslim and Jewish care needs, c) death certification issues, d) post-mortem examinations, e) planning for the end of life, f) conscientious objection of healthcare professionals.

7) A break followed by another small group session on the three subjects covered in section six.

8) A final open plenary session and summary.

During this period of research and development we began to advertise the course throughout hospitals in London, on the website of the Royal College of Physicians who gave it CPD (Continuing Professional Development) accreditation with each participant receiving 6 credits and also on the Woolf Institute’s website and through its Higher Education lists to ensure Muslim and Jewish studies students were made aware of the course. Each participant, as part of their application, was asked to fill in a pre-course questionnaire which included a request for a case study.
Part Two

Questionnaires and Evaluation

Our process of evaluation and reflection was three fold. Firstly, a pre-course questionnaire: this aimed to gather a sense of patient’s pre-existing knowledge and experience, allowing us to arrange group work and course material effectively. Secondly, an immediate post-course questionnaire, this was designed to gather immediate feedback, responses and recommendations. Thirdly, a follow up questionnaire. This form was sent out three months following the course and aimed to evaluate the relevance of course material within the context of participants working lives.

Results of Pre-Course Questionnaire

From the pre-course questionnaire 18 forms were returned from a total of 27 students. Questions included: statement of motivation, professional background, existing knowledge and confidence in dealing with end-of-life issues in this context. Answers to the latter tended to be extended and engaged, revealing a willingness to draw on personal experience to elaborate on the issues addressed. A number of these case studies were used during the day itself (with participants consent and preserving the anonymity of the patients in question) furthering the sense of the course being firmly situated within the Hospice in which it was delivered. For full responses and a complete list of case studies provided please see Appendix 3.

Within the questionnaire participants were asked about their expectations of the course. In addition to providing a statement of motivation, participants were asked: “How might a greater knowledge of end-of-life issues in Judaism and Islam help in your medical/nursing/pastoral care of the patient?” Most participants suggested a wish to deal with such issues more ‘sensitively’, commenting that they would like to use further knowledge to be more ‘mindful’ and ‘respectful’ of individual patient needs and outlooks. Another strong theme was the avoidance of conflict with family members, with several participants stating that they wished to acquire further knowledge in order to prevent conflict, reduce tension and to avoid causing needless offence. It was notable that several participant case studies participants illustrated how a lack of knowledge or confidence in addressing issues of faith could lead to serious break downs in family/hospital relations in the provision of End-of-life care.

Participants were asked to identify which areas of further knowledge would most benefit them. Four areas were emphasised in their response: withholding and withdrawing treatment, withholding and withdrawing nutrition and hydration, the use of language when liaising with Jewish and Muslim patients and their families, and issues around gender. Other issues, including: organ donation, death certificates, disposal of the body, definition of death, advance directives and interruption of pregnancy were also highlighted.

The second section of the questionnaire addressed issues of confidence regarding end-of-life issues in their work. This used a scaled response in which 1 = ‘no confidence’ and 5 = ‘extremely confident’ as a brief indicator of confidence levels in relation to different contexts (See Appendix 3, Q5). Firstly, participants were asked “How
confident do you feel in discussing the end-of-life issues with a Jewish/Muslim patient?” In relation to Jewish patients, 24% of participants felt that they had “no confidence” in discussing end of life issues, 35% felt quite confident and 24% felt confident. No participants felt “extremely confident” in relation to these issues. When the same question was asked in relation to Muslim patients a greater degree of confidence was suggested: with 35% of participants feeling confident, 35% feeling very confident and 6% feeling extremely confident. When asked “How confident do you feel in discussing the end-of-life issues with a Jewish/Muslim families” the responses were similarly distributed. 18% of participants felt that they would have no confidence in liaising with a Jewish family about a dying relative, 12% felt that they would have ‘little confidence’, 41% felt ‘confident’ and 29% felt ‘very confident’. No participants felt ‘extremely confident’ in this context. When the same question was asked in relation to a Muslim family the responses were somewhat more confident: with only 12% feeling that they had ‘no confidence’ or ‘little confidence’ and 35% feeling ‘confident’ and ‘very confident’. 6% of participants felt ‘extremely confident’ in dealing with this scenario.

The pre-course questionnaire offered a revealing insight both into the diversity of professional background and existing knowledge of those attending but also the variety of expectations and motivations for participating in this course. We anticipate that the use of pre-course questionnaire will continue to be important in the expansion of the course to new contexts: helping to ensure that course material draws on the experience and needs of the participants themselves.

Course Delivery

The pilot course was delivered at the Marie Curie Hospice on Wednesday 15th June 2011 between 9.30am and 5pm. In addition to Dr Henderson Davis and Andrew Brown from the Woolf Institute who delivered the course and the panel of health-care professionals and chaplains noted above there were also present the Woolf Institute’s Executive Director Dr Edward Kessler and Dr Shana Cohen, the Institute’s Stone Ashdown Director of the Centre for the Study of Muslim/Jewish Relations.

The course was attended by thirty-three people and included surgeons, doctors, nurses, psychologists, patient support staff, chaplains (Muslim and Jewish), social workers and students of Islamic and Jewish studies. We were also joined by Professor Stephen Mackinnon who leads the bone marrow and stem cell program at University College London.

Throughout the day the course was situated firmly within the context of current NHS and GMC guidelines and, by adopting a case-study approach, we were able to provide participants with greater knowledge of end of life issues in Islam and Judaism as they directly related to the medical and pastoral care of dying patients and their families. The case studies we used were drawn from extensive interviews with the panel members and from participants via our pre-course questionnaire. The structure of the day can be seen in the course timetable found in Appendix 1.

Each subject area was briefly introduced by placing it in the context of current varieties of Islamic and Jewish thinking (theological, philosophical and legal) so that the case studies could be understood both in relation to religious positions as well
current NHS and GMC guidelines. Following each introduction of a subject a case study was read and the panel were invited to comment upon it. Immediately after this there was the opportunity for additional questions and points from the course participants. After a coffee break we broke into four small groups and explored a further case study in greater detail. The groups then reconvened and, during the plenary session, the group leaders summarised their conversations before we opened up to the floor to explore more widely the issues covered during the morning as a whole.

After lunch we followed the same pattern but with different subjects and case studies.

Immediate post-course questionnaire and three month questionnaire

Responses to the immediate post-course evaluation were emphatically positive. 19 out of 27 respondents returned a completed evaluation form and the uniformity of the answers gave a strong impression as to the positive impact of the workshop. Many participants were struck by the idea of hosting a panel assembling professionals from different backgrounds and complimented the organisation of the workshop more generally. Comments included:

- I liked the use of case studies to initiate discussions and very much liked the ‘panel’ idea. The first course I’ve been on like this.
- A very well run course. A useful and rich panel and group that thought through issues delicately.
- It is really good to have a forum attended by multi-professionals to address these end of life issues.
- A very helpful panel with impressive range of professionals (esp. consultants!) and felt respectful of others.

The only repeated criticism of the course related to the size of the room in which the panel sessions were held, suggesting a need to ensure a larger room for those sessions in which all participants would be present. It was notable that most participants felt the course to have a direct relevance to their working lives. Out of the 18 respondents who answered this question two felt the material to be somewhat relevant to their work and 16 felt the course material to be very relevant. As Rabbi Bernd Koschland, Jewish Chaplain at the Royal Free Hospital and panel member commented: “As far as I was concerned, the day was most memorable. It enabled people from various disciplines to meet and talk together, discuss together and take new ideas and concerns on board. In this way, the time was not one for lengthy speeches resulting in a talking shop. It provided practical guidance and ideas for practical use. The Woolf Institute is to be congratulated for organising such a meaningful day.”

In addition to gauging the immediate impact of the course, the evaluation form was also used to collate suggestions for improving the course material. Suggestions included: the addition of case studies relating to organ donation, the inclusion of a greater diversity of contexts in case studies (from outside of an Intensive Therapy Unit setting) and the provision of further material to take away on religious principles on death and dying. In addition, some of the respondents offered suggestions for other courses that might be offered connecting faith to medical decisions, including workshops on mental health issues (specifically dementia and depression), the role of
pastoral care in making medical decisions versus professional counsellors, and how faith-based organisations can contribute to advanced care planning, both for older or younger patients. Two respondents also asked to include representatives of other religions and two mentioned adding a social worker and possibly a lawyer to the ‘expert panel’.

The overall sense was one of the necessity of addressing these issues and the greater confidence of participants to do so following an open and informed discussion. As Dr Phillip Lodge, Consultant in Palliative Medicine, the Royal Free Hampstead NHS Trust commented: “what struck me was that I learnt a great deal from the combined experience and knowledge of all the participants and other panellists. Conversations were open and no question was taboo. As well as highlighting the issues of particular importance to Jewish and Muslim patients and families, many other aspects of different beliefs and approaches to illness were raised. To deliver the best care, we must consider all aspects of a person’s needs and promoting a greater understanding of religious needs and values is essential if we are to achieve this aim.”

Three Month Follow-up Questionnaire

The final end of life questionnaire was sent out 3 months following the courses completion. This aimed to assess the impact and relevance of course material to participants working life. This questionnaire suffered from a diminished response rate, with only 11 out of 27 participants returning a completed form. Nonetheless, the qualitative response regarding course impact offered some insight into the diverse application of course material to participants working lives.

1. Course Impact

After stating their profession, participants were asked whether they had had the “opportunity to use information in the end of life course” in their work. Responses varied. Some found the course material directly applicable to their professional life:

“Yes I did [have the opportunity to use information learned] and do. I’m a Muslim myself and I look after Jewish patients on a daily basis. Certain information from this course helped me to understand my patients as Jewish views and practices regarding death differ widely. I’m more confident now in initiating end of life conversation with Jewish patient and his family or ask them openly about their expectations”

“I’ve learned in depth what end of life means to different people and the impact it has in their lives. I’ve been using the information learned in my current practice and have also shared it with my colleagues”

Two participants found that the course material did not have an immediate impact:

“Unfortunately there haven’t been any patients with a Muslim or Jewish faith requiring end of life conversations under my care since the course.”

“It is difficult to tangibly think how this was used. It was good to concentrate on the issues over a day but don’t think I particularly learnt anything new. The networking benefits though were useful.”
A number of participants, however, described the course impact in terms of increased confidence in discussing faith within the context of end of life care:

“I have had several discussions with families of Muslim faith since the course, around wishes at EOL and discussion of diagnosis of dying. I had increased confidence to approach these discussions and the language to use”.

“On approaching a Muslim family in ITU to seek consent for organ donation I felt more able to probe their responses and more comfortable discussing their faith and belief as a result of the course. I was also better prepared to meet their and their loved ones’ end of life needs”

For some this helped them to better understand the role of religious figures in end of life decisions:

“Yes, I am more aware of the religious, spiritual and cultural aspects in dealing with palliative care issues in Jewish and Muslim families. I am also more informed in terms of Rabbinical and Imam’s input in dealing with such issues.”

“I have had an end of life discussion with an Israeli family ad it really helped as I understood the relationship the family had with their rabbi and why they wanted to involve the rabbi in the discussion”

The general sense gained was of a well-received course that was largely relevant to participants working lives. It was notable that most expressed the application of this course not in terms of acquiring an exhaustive list of faith literacy information, but rather having the confidence to discuss these issues on an individual basis with patients and families themselves.

2. Confidence

The second section of the questionnaire addressed issues of confidence regarding end-of-life issues in their work using a scaled response in which 1 = ‘no confidence’ and 5 = ‘extremely confident’.

Firstly, participants were asked: “How confident do you feel in discussing end-of-life issues with a Jewish patient?” Responses for this question were wholly positive, with all respondent selecting answers within the 3-5 range (See Appendix 5, Graph 1) and the majority of participants selecting 4 (very confident). When the same question was asked regarding interactions with Muslim patients the results were similarly grouped, but with one further participant suggesting that they had “little confidence”. When asked: “How confident do you feel in liaising with Jewish families about a dying relative?” responses were similarly positive, with a clear majority selecting “very confident”, and one
“extremely confident”. All remaining respondents were “confident”. When the same question was asked of liaising with Muslim families the response was also positive: with three participants feeling themselves to be “extremely confident”, five “very confident and one “confident”. There was one participant who felt themselves to be “not very confident” in this field.

3. General feedback

The final question allowed for participant’s individual feedback, asking: “Are there any other comments you would like to make?” 10 out of 11 respondents gave further feedback, offering a wide range of comments and suggestions (See Appendix 5, point 5 for full list of comments). Of the suggestions for improvement two participants felt the day to be too “medically orientated” and two respondents suggested that the introductory sessions were too general. Similarly, while one participant felt the panel to be unhelpful, two participants commented on its usefulness, commenting that they “enjoyed the idea of the panel and the differing view points”. One specific suggestion from this section was offered by a participant who suggested that a greater emphasis should be placed on organ-donation in future sessions of this course. The tone was generally positive.

Conclusions

According to Carroll, ‘the importance of both religion and spirituality is that they provide a context in which people can make sense of their lives, explain and cope with their experiences and find and maintain a sense of hope, inner harmony and peacefulness in the midst of the existential challenges of life. Although for many people in living in Western societies dying is no longer situated within a formal, traditional religious context, for some communities holding an explicit religious worldview particular rituals and practices remain to the fore in their response to death and dying. This course examined responses to death, dying and end of life care with reference to Islam and Judaism.

When developing this course our perspective was framed by a number of concerns.

Firstly, we did not wish to present beliefs and practices of a particular community in a way that could make them seem strange and exotic or completely outside of general experience. Consequently, we took care to show that everyone lives according to some vision of the good life, and that non-religious ways of seeing the world also inform particular choices and decisions that lead people to behave in particular ways. Religious beliefs and practices are of this kind.

Secondly, we were also concerned to highlight the significant diversity of opinion within traditions, acknowledging the many different schools of thought, scriptural interpretation and different degrees of religious practice. We wished to show that it is not possible to reduce this complexity to a level where it was possible simply to say that a Muslim or a Jew believes such and such, and will want such and such to be done or not at the end of their life. Throughout we illustrated how both of these traditions arrive at certain conclusions about religious practice, and what kinds of impact this can have on decision-making at the end of life.
Thirdly, we wished to highlight how, throughout the course of their lives, the nature of people’s religious adherence may vary. Research has shown that as people approach the end of their lives the need for a spiritual dimension to life often increases (Brendan McCarthy, Why the NHS Needs Chaplains, November 2010).\(^5\) In the case of members of particular faith communities this can mean the adoption of greater religious observance, or the reversion to previous religious practices during the course of an illness.

Fourthly, we wished to make visible the way in which advances in medical care and technology will continually present new challenges, not only to the medical profession but also to particular religious beliefs and practices.

Fifthly, we wished to create a safe and creative educational space in which it was possible to ask very difficult questions and raise issues without worrying about whether one was saying the ‘right’ thing.

This report began with a number of aims to improve participants’ understanding of various issues. We will now return to these aims to assess whether they were met.

*The role played by religion in medical performance.*

The course illustrated many examples where religion had a strong impact upon medical performance. On the one hand it was possible to see that health-care professionals often felt ill-prepared or simply unable to address issues of religion and faith and their potential impact upon a patient’s end of life choices. On the other hand it was possible to see that patients and families who belonged to a religious tradition often felt unable to explain and talk about their religious needs with medical staff and were often fearful that these needs would be overlooked.

The course made it clear that NHS chaplains\(^6\) have a key role to play here not only in offering pastoral care to patients, families and medical staff, but also in mediating between the requirements of a particular tradition and those of the medical or care facility.

It became apparent, however, that although Muslim and Jewish Chaplains in the NHS are appointed to minister to members of their traditions across the spectrum of religious differences and divisions, some patients still wish to consult their own religious leaders, Imam or Rabbi. An issue which can arise when this occurs is that, although hospital chaplains are themselves well-versed in their own religious tradition's various bioethical opinions, this knowledge does not always extend to religious representatives who operate for the most part outside of a medical setting. Consequently, the hospital chaplain remains an important source of help and guidance for medical staff in trying to navigate the complex problems which can arise when relating religious practice and medical care.

\(^5\) [http://www.churchofengland.org/media](http://www.churchofengland.org/media)

\(^6\) Chaplains are salaried NHS employees and the NHS defines the work of the chaplain as that which ‘enables individuals and groups in a healthcare setting to respond to spiritual and emotional need and to the experiences of life and death, illness and injury, in the context of a faith or belief system.’ [http://www.nhsicareers.nhs.uk/details/Default.aspx?Id=532](http://www.nhsicareers.nhs.uk/details/Default.aspx?Id=532)
Thanks to the use of actual case studies and the fact that they were talked to by the panel the course was able to offer practical examples to participants about how they might proceed when a religious issue arose in a medical context.

*How Islam and Judaism can contribute positively to a wider societal debate on how to provide appropriate healthcare to an increasingly diverse population.*

Through both the research and development process and in the actual giving of the course it became clearer to us that although the issues we were exploring were grounded in Islamic and Jewish case studies the course was giving participants a more general way of understanding what it means to have any religious worldview and how that worldview can impact upon end of life decisions. By working through actual case studies drawn from a broad range of clinical settings, participants were invited to develop generally applicable skills and understanding in a way that improved their ability to offer good end of life care to patients from a variety of religious backgrounds. To make this aspect of the course clearer in our future promotion of the course we have changed its title from *End of life issues in Judaism and Islam* to *Diversity in End of Life Care: A Muslim/ Jewish Case Study.*

*The extent to which Muslim and Jewish patients rely upon their religious beliefs to cope with illness and death.*

The course illustrated the importance of never resorting to generalisations about what this reliance meant, or might mean, for a patient. Whenever a patient identifies as belonging to a particular religious tradition this can only be seen as the place to begin a conversation which could help both the patient and the medical staff agree an appropriate care pathway. However, this conversation must take with the utmost seriousness any religious beliefs expressed by the patient, not seeking to dismiss such beliefs as merely being of secondary concern when determining treatment.

*How end of life issues play out differently in different contexts and situations, i.e. hospitals, hospices, care homes and in patient’s own homes.*

The course illustrated the existence of differences between rushed and emergency contexts and those which were slower moving and more capable of being planned for. One important issue that arose in connection with this aim was the need for patients to prepare Advanced Directives and, in the case of new Muslims, a Statutory Declaration requesting a Muslim burial.

The need for effective hand-over arrangements was also highlighted. A good example being when a patient near the end of their life is allowed home arrangements should be made for the prompt issuing of a death certificate. It was also possible to see that in a hospice setting it is much more possible to be flexible about particular end of life care needs than in a hospital. Since within a hospice setting it is clearer to everyone concerned that a patient is approaching the end of their life.
The difference between theological and non-religious secular understandings of death, ownership of the body, informed consent, pregnancy and termination, conscientious objection, translation and other language issues.

The course clearly illustrated how differences between world-views can often be significant and apparently intractable. Through encouraging an on-going conversation, openly acknowledging the complexity and diversity of religious practice and belief, and also showing some of the key principles by which Islam and Judaism work through difficult biomedical questions, participants were encouraged to avoid making simplistic and inflexible assumptions of in what consists normative religious practice. The aim was to help participants recognise that there are likely to be other ways by which these real differences could be re-explored in different circumstances and/or at a later date.

The care of Muslim and Jewish patients and their families around such issues as gender etiquette, moment of death, post-mortem issues, death-certification and release of body and burial.

With respect to this aim the course contained within it basic faith-literacy information on all of these issues.

To conclude, as the course developed it became clear that a key course-outcome was as much to do with developing the ability of health-care practitioners and patients to talk and openly and with confidence about their individual needs as it was to do with teaching basic concepts of faith literacy (although this latter aim remains absolutely necessary if an informed conversation is to occur in the first place).

Having finished the pilot project the Woolf Institute team are currently employing all the evaluative findings and feedback contained in this report to help further develop the course before it is offered to other hospitals and hospices in the UK during the coming year.
Appendix 1
Course Timetable

End of Life Issues in Islam and Judaism
Marie Curie Hospice, Hampstead
15 June 2011
9.30am to 5pm

9.30 Registration and tea/coffee

10.00 Welcome

10.15 Session One
Part one
  Short general introduction including:
  • Sources of authority in Islam & Judaism
  • Basic principles

Part two
  • The role of chaplains – First case study with the panel
  • Withholding & withdrawing treatment, hydration & nutrition – Second case study with the panel
  • Definition of death – Third case study with the panel

11.30 Tea/coffee break

11.45 Session Two
  Working through an additional case study in small groups

12.15 Plenary Session
  Open discussion with feedback from small groups and questions and comments from the floor on the subjects from session one

1.00 Lunch

2.00 Session Three
Part one
  • Cultural vs religious issues – Fourth case study with the panel
  • Specific religious care needs – Fifth case study with the panel
  • Death certificates – Sixth case study with the panel

Part two
  Concluding topics
  • Post-mortem examinations
  • Planning for the end of life
  • Conscientious objection of healthcare professionals

3.15 Tea/coffee break
3.30  **Session Four**  
Working through an additional case study in small groups

4.00  **Plenary Session**  
Open discussion with feedback from small groups and questions and comments from the floor on the subjects from session three

4.45  **Concluding remarks, thanks and distribution of evaluation forms**

5.0  **Departures**

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**Panel**

**Mr Mahmoud Al-Akraa**  
Consultant Urological Surgeon

**Imam Ahmad Faruq**  
Muslim Chaplain, Barts & the London Hospital

**Rabbi Bernd Koschland**  
Jewish Chaplain, the Royal Free Hospital

**Rabbi Markus Lange**  
Resident Chaplain, Marie Curie Hospice, Hampstead

**Dr Philip Lodge**  
Consultant in Palliative Medicine, the Royal Free Hampstead NHS Trust, Marie Curie Hospice, Hampstead

**Elizabeth Thomas**  
Clinical Nurse Specialist

**Dr Adrian Tookman**  
Consultant Physician in Palliative Medicine, the Royal Free Hampstead NHS Trust, Medical Director, Marie Curie Hospice, Hampstead

**The Woolf Institute**  
Revd Andrew Brown  
Dr Claire Henderson Davis
Diversity in End of Life Care: A Muslim/Jewish Case Study

The GMC's current guidelines on end of life care state that discussions with patients should include:
- the feelings, beliefs or values that may be influencing the patient’s preferences and decisions.

In its 2008 End of Life Care Strategy, the Department of Health recognises that:
- many health and social care staff have had insufficient training in identifying those who are approaching the end of life, in communicating with them or in delivering optimal care.

This one-day course offers participants an opportunity to develop skills and knowledge to engage confidently with patients and their families in conversations about end of life care in cases affected by religious beliefs and practices. Using the examples of Islam and Judaism, this course gives an understanding of what it means to have a religious worldview. By working through case studies drawn from a broad range of clinical settings, participants will develop the necessary skills and understanding required to offer the best end of life care to patients from different religious backgrounds.

Academic staff from the Centre for Public Education at the Woolf Institute lead the course in conjunction with an expert panel comprising a doctor, a nurse and a Muslim and Jewish chaplain working in relevant clinical settings, ideally, from the hospital or institution in which the course is offered. Dr Philip Lodge (Consultant in Palliative Medicine, the Royal Free Hampstead NHS Trust, Marie Curie Hospice, Hampstead) is the course’s permanent clinical advisor.

Subjects covered will include:
- What it means to be religious
- Withholding & withdrawing treatment, nutrition & hydration
- Definition of death
- Cultural vs. Religious Issues
- The role of Chaplains

The course has received 6 CPD credits from the Royal College of Physicians.
The Woolf Institute will reapply for this accreditation for each course delivered.

For more information, please contact:
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Wesley House, Jesus Lane
Cambridge CB2 3JF
www.woolf.cam.ac.uk
Charity number: 3540878
Dr Philip Lodge, Consultant in Palliative Medicine, the Royal Free Hampstead NHS Trust, Marie Curie Hospice, Hampstead: “As a panellist what struck me was that I learnt a great deal from the combined experience and knowledge of all the participants and other panellists. Conversations were open and no question was taboo.

As well as highlighting the issues of particular importance to Jewish and Muslim patients and families, many other aspects of different beliefs and approaches to illness were raised.

To deliver the best care, we must consider all aspects of a person’s needs. Promoting greater understanding of religious needs and values is essential to achieving this aim.

I commend The Woolf Institute team for the great effort they have made.”

Rabbi Bernd Koschland, Jewish Chaplain, the Royal Free Hospital: “The day was most memorable. It enabled people from various disciplines to meet and talk and take new ideas and concerns on board. In this way, the time was not one for lengthy speeches resulting in a talking shop. It provided practical guidance and ideas. The Woolf Institute is to be congratulated for organising such a meaningful day.”

Mr Mahmoud Al-Akraa, Consultant Urological Surgeon: “The one-day course was an excellent and enriching educational day about end of life issues in Islam and Judaism. Understanding religious beliefs, views and culture in this context are very important issues for me and will help in dealing with families and relatives during a very difficult and stressful time.”

Quotes from participants:

- I really enjoyed the whole day. Real eye opener!

- A very well run course. A useful and rich panel and group that thought through issues delicately.

- A very helpful panel with impressive range of professionals (esp. consultants) and felt respectful of others.

- Good to have the opportunity to interact with people from different backgrounds. I’m now more confident to discuss religious issues with families within my role.

- I liked the use of case studies to initiate discussions and very much liked the ‘panel’ idea. The first course I’ve been on like this.

- It is really good to have a forum attended by multi-professionals to address these end of life issues.
Appendix 3  
Pre-Course Questionnaire Responses

- 18 forms returned from a total of 27 students.  
- All responses included.  
- [ ] represents those questions which were left blank.  
- Participant number refers to the number given to each hardcopy.

Q1. STATEMENT OF MOTIVATION

Please tell us why you wish to join this programme and what you hope to gain from the day.

P1: [ ]

P2: I would like to know more about Islam and Muslim beliefs in end of life issues.

P3: Many of the families I approach and support are members of the Islamic or Jewish faith. I order to support them appropriately and respect their and their loved ones beliefs I felt this programme would be ideal.

P4: To learn more about working with end of life issues when seeing patients and families.

P5: [ ]

P6: I wanted to learn more about the spiritual needs of Muslim and Jewish patients at the end of life so that I can be better equipped in my work at hospice care.

P7: I work at a Hospice where we provide care for a large community which involves Muslim patients as well. I would like to be better prepared to communicate with them about end of life care. In my second workplace, I have met Jewish patients. I wish to know how to provide care for them, especially given that most of my patients are elderly and frail due to older age.

P8: [ ]

P9: I am responsible for spiritual care, social work and volunteer support. We work from a Multi-Faith and no-Faith perspective- so I am interested in integration, whether around faith or discipline- ensuring strong individual identities strengthened to combine.
P10: To learn more about the different religions and how that impacts on the care I provide as a palliative care nurse. I want to be able to apply my knowledge to enhance my skills when dealing with patients and families with palliative and end of life care needs.

P11: I hope to deepen my awareness of key end of life issues for both Jewish and Muslim Patients & family members. It is my responsibility to ensure high quality Spiritual & Religious End of Life Care for Palliative Care / Hospice Patients.

P12: I’m interested as to how the context of Islam and Judaism affects choices people make at the end of life and how this also connects with familial experiences/responsibilities/expectations. I’m also interested as to how psychological support may be viewed in the context of people and families who hold religious beliefs from an Islamic or Jewish faith. I’m generally interested in hearing more from perspectives that are different than my own.

P13: I have some familiarity of working with Muslim patients and families from working in tower hamlets, but less experience of working with Jewish patients. When issues related to a patient’s faith become complex they are frequently referred to psychology. I would like to gain a broader perspective on the issues and concerns that are important for Muslim and Jewish patients and families on spiritual, emotional and practical levels, as psychologists often become the interface between patients and medical teams on these issues, and I frequently feel my knowledge is insufficient.

P14: To gain insight into the cultural beliefs and practices that might influence my practice in end of life care.

P15: As a Chaplain working in the NHS, I would wish to gain knowledge and skills in getting the information across to staff and families.

P16: [ ]

P17: I have encountered wishes and beliefs about death/dying whilst caring for Muslim and Jewish patients that I am not so familiar with e.g. – distress around diagnosis of dying. I would like to be more confident in addressing these issues sensitively and gain a better understanding of the issues at end of life issues.

P18: Very little experience working in a culturally diverse society. New role requires increased knowledge.

Q2. Profession (selected from list):

| Doctors: 5 |
| Nurses: 5 |
| Psychologists: 3 |
| Chaplains: 2 |
| Other: 2 |
| Not stated: 1 |
In your professional life have you encountered a Jewish patient whose faith had an impact on decisions about their medical and/or nursing care? If so please give an example (excluding names) which may be used for discussion within the programme.

P1: No.

P2: No.

P3: I have not encountered a Jewish patient where their faith had an impact on their care, but I have approached a patient’s family regarding the option of organ donation. The patient was in ITU and the decision had been made to withdraw treatment. I approached the patient’s husband and daughter about donating the lady’s organs for transplant. The family, especially the husband, flatly refused. I tried to give information that for example many Jewish families have donated but they felt very strongly that it was totally against their faith.

P4: No.

P5: No.

P6: I have come across a Jewish patient who was imminently dying whose family were reluctant to accept that this was the case. The family demanded that intravenous fluids be continued as they were under the impression that death would be caused by dehydration. However careful discussion did not result in the withdrawal of I.V. fluids particularly when retained secretions became difficult to control as the patient was by now unconscious and unable to cough. There have been similar situations in my experience with other Jewish patients, especially with those who were more overtly religious. This is in common with some Muslim attitudes also. However I have also experienced similar situations with Christian patients and those who profess to have no faith so I don’t feel I can generalise.

I have also come across secular Jewish patients who were keen to have ‘natural deaths’ and did not want life to be prolonged when the dying process became irreversible. These patients sometimes opt for cremation rather than the traditional burial but other rituals have been important, drawn from Jewish or other personal belief systems (in one case Buddhist).

P7: I have very limited experience with Jewish patients.

P8: I have only really had end of life situations with people of the Jewish faith where it became a real issue due to handover period. At the time I didn’t know what that really meant for me or the family.

P9: [ ]

P10: [ ]

P11: Yes. I have encountered dying Jewish patients/family members who insisted on continuing feeding/treatment, even though clinically it was clear that the patient was
dying and that such treatment would not prolong life, but could contribute to increase anxiety or distress. Even attempts to explain as sensitively and gently as possible were met with negative critical reaction and the threat of making a formal complaint.

P12: None experienced.

P13: I worked with a Jewish woman diagnosed with lymphoma. The consultants were very keen for her to proceed with chemotherapy and gave her a 70% survival rate. However, she wanted to delay a start to treatment as her quality of life was more important to her than prolonging her life by X number of years, so she was referred to psychology for “concordance with treatment”. She also challenged their medical model of cause – symptom – treatment and saw it as too linear and was more interested in managing her disease through her lifestyle and mind-body links. The medics found it difficult to accommodate her views and still be responsible for her care.

P14: I was involved in a 99 year old Jewish patient who had a large myocardial infarction whom the medical team felt was unlikely to survive in the event of another cardiac arrest. His son was insisting and confrontational that CPR was carried out regardless in such event on the basis of his religious belief. He was threatening a legal action. The events happened over the course of several hours. When the patient arrested again, his son was present on the ward and a cardiac arrest team was called to resuscitate despite the likely futility: the patient failed to survive.

P15: [ ]

P16: No encounter where Judaism has directly impacted on patient’s clinical care.

P17: 55 year old Jewish lady, with metastatic disease being cared for in a hospice at EOL, prognosis very short – days-weeks. Large supportive family, with strong Jewish faith – Orthodox. Decisions around the ceiling of treatment, and how much treatment to give if deteriorates/dying at end of life quite difficult. Family wished for all possible treatment eg Abx/ fluids to prolong life even if only for a very short time. Felt every second of life precious. Medical team concerned that such treatments would cause more harm than good, and might not be in patient’s best interests. Agreement made that patient would not be for resuscitation, but would be for IV fluids/antibiotics if family had strong wishes for this at EOL, as may lead to greater problems in bereavement for family.

P18: No experiences to share.

b) Muslim Case Studies

In your professional life have you encountered a Muslim patient whose faith had an impact on decisions about their medical and/or nursing care? If so please give an example (excluding names) which may be used for discussion within the programme.

P1: Yes. A 48 yr old female patient with end stage pulmonary fibrosis. The husband and family stated the patient had expressed her wish to them not to have prolonged
ventilation in ITU as whatever was wrong with her was God's will and being placed on a ventilator in ITU would not change this; indeed it would prolong her suffering. The husband and two children supported her position.

P2: We have had babies where the situation was very bleak and they have not either wanted to be with the baby or wanted the tube taken out until there was no heart rate. I suppose we would like all babies to be held by their parents if they can.

P3: Nil experiences I’m afraid.

P4: Patient who was clearly dying, but he and his family would not talk about this. Have seen this frequently when working with Muslim patients and their families.

P5: No.

P6: Again, there have been a variety of attitudes from Muslim patients and their families so I feel I cannot generalise. One attitude I have come across is that if they pray hard enough or follow rituals exactly, life will be preserved. Of course, the patients died despite this. Again, I have come across this in religious Christians also.

One young man who was dying of colon cancer was extremely frightened. He had a bottle of holy water by his bedside. The Imam visited and prayers were said regularly in Arabic which he did not understand. I think he found this comforting to an extent but was still traumatised by his illness. I asked him what the Imam had said to him and he replied that he had been told that he must do all he can to live. There was no preparation or acceptance that death would come. His father and brothers were angry and distraught all the time, trying to dictate medical intervention when there wasn’t any that would make a difference (eg. Albumin infusions) which we were able to desist from doing by careful and repeat explanation. They required a lot of support from the medical team and constant reassurance that we were acting in the patient’s best interests. They refused to accept that death was imminent as doctors had got it wrong before. The patient’s mother could not speak English and the husband and other sons kept her in the dark about how ill her son was although I am sure she discerned this anyway. As a Muslim but not of the same background or language I did by best to pay attention to her – I think she did get some comfort from this as her face used to light up when she saw me but she looked frightened. When the patient did die, a keening sound came from his room as all the family expressed their horror (although the death itself was peaceful). The actual death came as a shock to them but they had been preparing for it without knowing it – the Imam had been coming more frequently and more family members visited in the few days before.

P7: The patient was a 55 year old [Muslim] lady with advanced ovarian cancer and in total obstruction. Family was translating for her as she didn’t speak English. Admitted to hospice for symptoms control of pain, vomiting and nausea. Family (husband and 4 kids age 17 to 24) very distressed on admission as couldn’t believe that they can’t do anything for their mother (operation, NG feeding, IV drips). ~Whole family had bad experience from other healthcare setting. They were very anxious and unhappy regarding pain management. They felt also that hospice staff is trying to make patients life shorter. Family couldn’t accept her being sleepy and drowsy despite good symptom management. They requested reduction of painkillers, antiemetics and later
refused despite patient’s pain and agitation. Husband and son stated that she should be conscious enough to pray and later recite Shahada before she dies. They wanted to be informed every time when nursing staff was about administer any kind of medication to her and quite often husband or son didn’t allow it. Once whole family decided to take patient home and seek for second opinion in private healthcare. Patient was admitted to the hospice 3 days later as emergency admission with terminal agitation. Family was in panic at this time and after 2.5hr conversation with consultant accept syringe driver to administer medication but still carefully checking medication, searching in internet and trying “negotiate” doses or alter medication. Patient died few days later

P8: Sometimes in diagnosis and difficult family discussions the Muslim faith has been very supportive to them to help deal with the situation.

P9: Most of my professional experience has involved supporting others to carry out work with families including Muslim families- carefully recruiting and training staff so that BME communities are represented in the service.

P10: Looking after a [Muslim] patient after they had died. The patient had had a big bleed prior to dying and the family insisted on washing the patient themselves. Difficult as the patient had an open wound which was very upsetting for them to see.

P11: On occasion, observant Muslim patients or families have asked us to ensure that certain types of medication (e.g., insulin or mouth sprays) do not contain pork products or derivatives. This has also been requested occasionally by Jewish patients and/or families.

P12: None, only indirectly.

P13: I can’t think of one specific example but themes have been: families concerns to preserve a patient’s dignity, rather than purse further treatment at all costs; withholding information, so that the patient or particular family members are not told key pieces of information. Dignity on the ward in relation to gender of patients and staff.

P14: [A Muslim patient] with a background of severe dementia, several CVAs, immobility with contractures and recurrent aspiration pneumonia. He was admitted in extremis with severe pneumonia and was admitted. There was a disagreement with the family and medical team in terms of his resuscitation status and ceiling of care. His family was insisting that he should be for all treatments including CPR and ITU on the basis of religious belief in the sanctity of life. Medical team felt that CPR and ITU would be a futile option and unacceptable. Several family meetings involving senior doctors and family with religious leader mediation to reach a decision. The conflict introduced a stressful environment of care for family and medical team.

P15: A young Muslim man had tried to commit suicide. He thought that what he had done was so terrible that Allah would never forgive him. As a Muslim Chaplain, I gently relayed the teachings on Allah’s love and Mercy, which is beyond human comprehension. This in turn gave him new hope and encouragement to revaluate his
life and gain the will to live. A week later he walked out a new man, having contacted the relevant people, sorting solutions to the situation. Although in this case faith may not have had a direct impact on medical grounds, calling in a faith representative, helped aid recovery on more than the physical level.

P16: [ ]

P17: 70 year old Muslim lady, refractory AML. Several hospital admissions over last weeks of life, with sepsis. Started on the LCP and taken off LCP on 2 occasions – party because of family’s wishes. Family, especially her son found it difficult to accept the treatments were no longer working and were futile. Felt that medical/nursing team couldn’t diagnose when the patient was dying and therefore didn’t agree with the withdrawal of e.g. Abx, fluids, Oral chemo – even though some felt to be doing more harm than good e.g. –GI upset. Being started and taken off LCP, strengthened their views. Patient herself unwell, and no strong wishes about treatment, didn’t speak English so communication more difficult, although seen with advocate. Family also wanted to be informed of all medication changes and refuse treatments if possible. Patient had problems with abdo pain responsive to opiates – but at one point during admission, the patient’s son would not allow nurses to administer analgesia as they felt it was hastening death (NB for this reason on Oxynorm 0.5-1mg s/c – reduced dose). Eventually deteriorated further, with acute renal failure. Family meeting – discussed again seems at EOL, family not in agreement, agreed to continue fluids/diuretics as has rallied before, but passed away later that day. Family did thank ward and team for care after death, despite difficulties during admission.”

P18: Impact was more on social care and discharge planning. The lady didn’t want to leave the in-patient unit until she was walking and due to disease progression and muscle weakness this was highly unlikely. I felt very awkward discussing the likelihood that the lady wouldn’t walk again and what to expect from therapy but the family would not accept that she would not get better

Q4. Knowledge

Have you attended other courses about end of life issues and faith? Yes /No

No: 8

Yes: 8

Courses attended: Bliss study days⁷ on palliative care, University courses on end of life care, in-house study days, internal courses and academic conferences and lectures.

Left blank: 2

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⁷ Bliss is a national charity dedicated to improving both the survival and long-term quality of life for premature and sick babies.
Where does your existing knowledge of other religions come from?

Sources of existing knowledge of other religions

- Mixing with colleagues
- Professional Experience
- Home community
- Media
- Books
- School Memories
- Previous training courses
- Hospital chaplaincy outreach
- Other
In which of the following areas would you benefit most from further knowledge of Jewish and Islamic views?

- Conscientious objection by healthcare professionals: 5
- Organ Donation: 7
- Death certificates: 4
- Disposal of Body: 7
- Definition of death: 10
- Advance Directives: 8
- Interruption of pregnancy: 5
- Withholding and withdrawing nutrition and hydration: 13
- Withholding and withdrawing treatment: 15
- Issues around gender: 12
- The use of language when liaising with Jewish and Muslim patients: 14
- Other: 1
How confident do you feel in discussing the end-of-life issues with a Jewish patient?
Scale: 1-5 (where 1= no confidence and 5= extremely confident)

What issues in particular do you find difficult to discuss? Please specify:

P1: Any limitation to organ support e.g. ventilation, dialysis.

P2: [ ]


P4: Talking about dying to patients and families whose cultures do not believe in doing this.

P5: Everything- as I’m relatively new to working in this area.

P6: I feel that many concerns are universal at the end of life regardless of faith and if it something I don’t know I would ask. However I do feel I need more knowledge about religious rituals in order to anticipate needs.

P7: Advance care planning, nursing care during Shabbat, end of life care, withholding treatment and nutrition.

P8: Life after death and the process.

P9: I am not employed as a practitioner –but my role is to enable others to work with Muslim families encountering end of life.

P10: Not sure I know enough about their religion.

P11: Different strands of Judaism lay different emphasis on different customs. Trying to find what is important to the patient takes sensitivity and time.
P12: I haven’t experience this although I believe in my role it would be how I support staff if clients viewpoints are very different from those held by staff/medical perspective.

P13: Most concern at displaying my ignorance at whether specific rituals or considerations are important.

P14: [ ]

P15: [ ]

P16: My previous discussions about end of life issues with Jewish relatives had been fairly straightforward where religion itself has not been specifically discussed.

P17: Discussing that death is approaching, and wishes around this, ceiling of treatment.

P18: All, have had no experience with Jewish faith or Jewish communities. Wouldn’t want to offend.

**How confident do you feel in liaising with Jewish families about a dying relative?**

Scale: 1-5 (where 1= no confidence and 5= extremely confident)

![Confidence Chart]

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**What issues in particular do you find difficult to discuss? Please specify:**

P1: Unsure about their response to palliative therapy

P2: Withdrawal of care, ventilation.

P3: As above (Definition of death, unacceptance of breath [sic] stem death. Chief Rabbi’s view on donation and definition of death). Plus understanding re the need to bury the body within 24 hours.

P4: Nothing in particular, but issues may come up for which I was not prepared.
P5: Everything- as I’m relatively new to working in this area.

P6: As above (I feel that many concerns are universal at the end of life regardless of faith and if it something I don’t know I would ask. However I do feel I need more knowledge about religious rituals in order to anticipate needs.)


P8: [ ]

P9: [ ]

P10: Not sure I know enough about their religion.

P11: Some families are very sensitive about the use of the “D” word (death or dying). Trying to find the balance between respectful sensitivity and professional honesty about the reality of the patient’s situation can be difficult. Each patient/patient’s family must be treated separately and with no assumptions.

P12: [ ]

P13: I have less exposure to families in a ward environment as I am oncology vs palliative-based.

P14: [ ]

P15: [ ]

P16: [ ]

P17: [ ]

P18: All, have had no experience with the Jewish faith or Jewish communities. Wouldn’t want to offend.
How confident do you feel in discussing the end-of-life issues with a Muslim patient?
Scale: 1-5 (where 1= no confidence and 5= extremely confident)

What issues in particular do you find difficult to discuss? Please specify:

P1: [ ]

P2: Withdrawal of intensive care

P3: Understanding re the need to bury the body within 24 hours.

P4: As above: (Nothing in particular, but issues may come up for which I was not prepared.)

P5: Everything- as I’m relatively new to working in this area.

P6: There are such a range of beliefs, I would not presume to know what the spiritual/religious needs are.

P7: Withholding treatment, gender issues (male nurses on duty).

P8: [ ]

P9: [ ]

P10: Not sure I know enough about their religion.

P11: [ ]

P12: Language and using interpreters is definitely a big issue (for families being used as an interpreter) in Tower Hamlets with the Bengali population who are Muslim. Introducing psychology (sic) support remains difficult due to cultural differences and understanding of what psychology means.

P13: Spiritual- theological aspects- e.g. life after death; earning Allah’s approval through deeds.
P16: Withdrawing of nutrition and hydration.

P17: As above (Discussing that death is approaching, and wishes around this, ceiling of treatment) – and difficulties around the withdrawal of treatment.

How confident do you feel in liaising with Muslim families about a dying relative?
Scale: 1-5 (where 1= no confidence and 5= extremely confident)

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<td>2</td>
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<td>3</td>
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<td>4</td>
<td>41%</td>
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<tr>
<td>5 (extremely confident)</td>
<td>6%</td>
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What issues in particular do you find difficult to discuss? Please specify:

P1: The Islamic position on limitation of medical support e.g. ventilation, dialysis.

P2: Understanding their beliefs in end of life care.

P3: [ ]

P4: Need to check out where they are at and their belief system before I would know what difficulties I might encounter.

P5: Everything- as I’m relatively new to working in this area.

P6: As above (There are such a range of beliefs, I would not presume to know what the spiritual/religious needs are.)

P7: Addressing post death care with families, advance care planning, withdrawing treatment.

P8: [ ]
P9: As above – I am not a front line practitioner- but if I were the difficulty would be about knowledge of the faith- and what would feel meaningful to the patient/family.

P10: Not sure I know enough about their religion.

P11: [ ]

P12: See above: (Language and using interpreters is definitely a big issue (for families being used as an interpreter) in Tower Hamlets with the Bengali population who are Muslim. Introducing psychology (sic) support remains difficult due to cultural differences and understanding of what psychology means.) Engaging seems to be a big problem, particularly when interpreters may be required. Having a sense of the emotional support needs.

P13: Concerns re confidentiality

P14: [ ]

P15: [ ]

P16: Withdrawing of nutrition and hydration.

P17: [ ]

P18: When treatments are no longer appropriate.

How might a greater knowledge of end-of-life issues in Judaism and Islam help in your medical/nursing/pastoral care of the patient?

P1: Being aware of beliefs and issues will help to understand their position, and having knowledge of the background of their beliefs will help giving an explanation for our work. Also having knowledge of their beliefs can help me in providing alternative healthcare treatments which may not conflict with their beliefs.

P2: To be a better support to patients by understanding their support mechanisms. I know I work in the neonatal unity, but I am hoping for a greater insight into both religions in order to give parents greater empathy to their situation.

P3: Approaching and supporting families more sensitively. Fully respecting the religious wishes of patients and their families.

P4: Enable me to give better and more sensitive to patients and families.

P5: It will enable me to be mindful and respectful of the needs of both religious groups when working.

P6: I do not now work in an area where there are many Jewish or Muslim patients so the opportunity to learn through experience is limited. I would feel better equipped when Muslim and Jewish patients come my way.
P7: Better care provided to patients as understanding and respect helps handle difficult situation and reduce tensions on both sides.

P8: To feel more comfortable dealing with families.

P9: As above (I am not a front line practitioner- but if I were the difficulty would be about knowledge of the faith- and what would feel meaningful to the patient/family).

P10: Help with end of life care for those religions. Being aware of what is important to these patients and their families.

P11: Patients and family members often feel safer when engaging with someone both sensitive and knowledgeable about the end of life issues pertaining to their faith.

P12: I’m not a trained medical professional but support my colleagues when a psychological account or version of challenges/difficulties that may be faced by a person/family/professional may help. Understanding some of the issues that arise for my medical colleagues would be helpful in enhancing how I might be able to help. Enhancing my own (sic).

P13: As I work in oncology, and particularly with haematology patients on the wards where their death can be sudden and traumatic, or their disease trajectory is less certain, the palliative care team are not involved and I am one of the few “non medics” involved, thinking holistically about patients care and their spiritual wellbeing and practices. Greater knowledge in this area would equip me to think with staff about this earlier in patients pathways and to equip (especially nursing) staff to be more aware of these issues.

P14: To understand it from patients religious perspective to provide what the patient wants in their end of life care. To avoid conflicts and offending patients and family unintentionally.

P15: Confidence.

P16: To have a better knowledge and understanding of Jewish and Islamic laws on medical ethics will be of great help when it comes to discussing end-of-life issues with patients and relatives. This will enable me to provide a more ‘rounded’ care.

P17: Increase confidence in sensitively broaching issues around EOL, and not causing distress to patients and families. Also so we can work with MDT/ward teams to also ensure that they are aware of these issues.

P18: Be able to offer more appropriate support.
Is there any other information you would like to add?

P1: [ ]

P2: Hope the above makes sense. I have not seen any study days based on these specific religions and I am looking forward to learning more.

P3: [ ]
P4: [ ]
P5: [ ]
P6: [ ]
P7: [ ]
P8: [ ]

P9: It may be worth considering issues of management and supervision in developing the right response.

P10: [ ]
P11: [ ]
P12: [ ]
P13: [ ]
P14: [ ]
P15: [ ]
P16: [ ]
P17: [ ]
P18: [ ]
Appendix 4
Immediate Post-Course Evaluation Returns

- Participant number relates to the number given to each hardcopy.
- All responses included: [ ] represents those questions which were left blank.
- 19 forms returned from a total of 27 students and 7 panel members present.

Q1. Did this course meet your expectations? If not, explain.

P1: Yes (even more)

P2: Yes, I really enjoyed the whole day. Real eye opener!

P3: Mostly- perhaps more actually about the values + beliefs of Islam and Judaism- practically caring for patients.

P4: Yes. Enjoyed the panel’s discussion. Informative.

P5: Yes and more. A very well run course. A useful and rich panel and group that thought through issues delicately.

P6: Yes, very helpful panel with impressive range of professionals (esp. consultants!) and felt respectful of others.

P7: Emotive topics. Liked case studies to initiate discussions, very much liked the ‘panel’ idea- first course I’ve been on like this. Great to hear individual specialist opinions.

P9: Not fully. I found some case studies not relevant to the 2 faiths. I was hoping for more faith background to give me better understanding for rationale for actions at the end of life.

P10: [ ]

P11: Was not sure what to expect, but found it good.

P12: Yes. Useful to have open discussion from various professionals Re. Religious + cultural aspects of end of life care.

P13: Yes. Highly impressive panel.
P14: Yes.
P15: Yes.
P16: Yes- excellent.
P17: Generally a good overview of the faiths. Good to have the opportunity to interact with people from different backgrounds. Am now more confident to discuss religious issues with families within my role.
P18: Yes. It is really good to have a forum attended by multi-professionals to address these end of life issues.
P19: Yes.

Q2. Were you satisfied with the organisation of the course? If not, explain.

P1: Yes (Very well organised, thank you) I liked the mixture of panel and small groups. The small groups- at least mine- were very well put together (variety of view points).
P2: It was too hot at times at conference room.
P3: Room very hot! Otherwise well organised.
P4: Yes.
P5: Yes. Very punctual. Keeping on time was overall useful to get through all the material.
P6: Yes.
P7: Yes.
P8: Yes.
P9: Yes, although the room was very hot which made uncomfortable listening at times.
P10: Room was too hot.
P11: Yes.
P12: Yes.
P13: Yes. Except, perhaps, the use of facilitators rather than a chair may have allowed us to drift into the general.
P14: Yes.

P15: Perhaps it would have been helpful to have longer time in small groups and slightly less time within main group.

P16: Yes- excellent.

P17: Well organised.
      Pack very useful.
      Clear plan for the day which was adhered to in a timely manner.

P18: Yes, very well organised.

P19: Yes. But there should be more participation from the delegates/audience. The “panel” approach felt a bit like question time. Perhaps wider membership of the panel.

Q3. What material do you think needed to be added, if any?

P1: [ ]

P2: More case studies?

P3: [ ]

P4: A little more information on rituals involved. Especially family customs.

P5: Possibly less on more ‘cultural’ issues, e.g. interpretation+ more on specifically faith related issues.

P6: Would have been helpful to have a bit more didactic teaching early on in Islamic and Jewish principles, r.e. death/dying form a theological view point. Perhaps more variety in teaching methods, other than case discussions.

P7: Perhaps handouts for some of the specific legislation quotations.

P8: A bit more background theory may have been useful? prior to course for reading.

P9: Background information on faiths – Muslim – Jewish.
      Correct language to be used at End of Life for target group.

P10: More info on specific needs of the patients dependent on religion at the End of Life.

P11: Perhaps slightly less panel discussions and more small groups.

P12: Powerpoint presentations.
      Perhaps patients viewpoints/experience, or relative experience/perspective.

P13: Possibly (only possibly) a little more opening formal input from Jewish and Muslim panel members.
P14: I think it was good.

P15: It would be really good to have a lawyer on the panel as the number of statements made such as “English law says”, “the GMRC guidelines”. Another seminar please!

P16: More practical information about rituals around death- checklist.

P17: Discussion r.e. organ donation should form part of the end of life care for all patients where appropriate. I was disappointed that this was not a specific topic of discussion, especially as relative refusal in these specific groups is high. A specialist nurse in organ donation would be very happy to be on the expert panel for any future events.

P18: I don’t think anything additional needed to be added. It was a very full and comprehensive agenda.

P19: Nil

**Q4. Do you feel that the topics and case studies discussed were relevant for your own work?**

P1: I got a lot out of the day for my congregational work.

P2: Yes, very much.

P3: []

P4: Case discussions were very good- especially the ones about younger patients and the relatives. Use of interpreters/duty of care.

P5: Yes.

P6: Yes, death certificates possibly the least useful.

P7: Perhaps a more varied clinical environment for case scenarios… remember several being in ICU [Intensive Care Unit] setting.

P8: Yes.

P9: Some.

P10: Yes.

P11: Yes.

P12: Yes. Completely.

P13: Yes.
P14: Yes.
P15: Most definitely.
P16: Yes.
P17: Highly relevant. But apologies for going on about donation (!) A case study relating to donation I think would have been interesting and stimulated debate.
P18: Yes.
P19: Yes.

Q5. Are there other related topics such as, for example, caring for the elderly within different faith communities that you would like to see developed into courses?

P1: I liked the practical approach (that it was not just a theological dialogue.) Other themes may cover:
- pastoral care versus counselling/psychotherapy
- gender issues (role of men/women in Judaism and Islam)

P2: Mental health problems (dementia, depression)

P3: [ ]
P4: [ ]
P5: [ ]
P6: [ ]
P7: [ ]
P8: N/A

P9: ‘Young People’ who have beliefs- how different for older family members. Advanced Care Planning. Explantion of faiths.

P10: Jehovah’s Witnesses.

P11: Would be useful.

P12: Yes: dementia care/ end of life issues in Elderly & Dementia within Multifaith community.

P13: This is a bias from my own trade but I think a social work contribution might have helped, especially knowledge of bereavement literature.
P14: Death and potential organ donation. Case studies to improve awareness and increase donors

P15: [ ]

P16: End of life issues in dementia care.

P17: [ ]


P19: [ ]

Other comments:

P4: Thank you for showing initiative in setting this up. An enjoyable day.
Appendix 5
Post-Course Questionnaire: 3 months on

1. How confident do you feel in discussing end-of-life issues with a Jewish patient?
   (where 1 = no confidence and 5 = extremely confident)

   ![Bar chart showing confidence levels for Jewish patients]
   - 0 respondents rated 1
   - 0 respondents rated 2
   - 3 respondents rated 3
   - 6 respondents rated 4
   - 1 respondent rated 5

2. How confident do you feel in discussing end-of-life issues with a Muslim patient?
   (1 = no confidence and 5 = extremely confident)

   ![Bar chart showing confidence levels for Muslim patients]
   - 0 respondents rated 1
   - 0 respondents rated 2
   - 3 respondents rated 3
   - 4 respondents rated 4
   - 2 respondents rated 5
   - 1 respondent selected No response

11 respondents in total
3. How confident do you feel in liaising with Jewish families about a dying relative?  
(1 = no confidence and 5 = extremely confident)

4. How confident do you feel in liaising with Muslim families about a dying relative?  
(1 = no confidence and 5 = extremely confident)
5. Are there any other comments you would like to make?

1. We need more study days like this.

2. I particularly enjoyed the idea of the panel and the differing view points. I didn’t feel like I got a real sense of the specific difference religious beliefs, the overview at the beginning was far too quick and a lot of information was missed. Whilst I appreciate the message of the day was more about the differing beliefs within a religion I was hoping to come out with a better sense of the fundamental differences between the religions for the religious groups.

3. I am sorry it is my responsibility for not feeding back sooner and now I find it quite difficult to remember 6 months later. I think my experience of this form resonates a bit about the day. I didn’t feel connected in my role – though appreciate I may have been attending a day more geared to practitioners. It was also extremely medically oriented – very little voice given to psychosocial/psycho-spiritual – MDT. I remember the room was extremely warm and the in the room sessions were very long. The style of the day set up an ‘expert’/’the rest’ dynamic which I didn’t think was very helpful i.e. it didn’t lead to discussion where dilemmas could be processed. I disagreed with many of the answers or wanted a fuller process. It felt laborious going through each person to give their response each time and I didn’t think they were probably any more ‘expert’ than anyone else in the room. The process was over contained and noticed some panel members were showing their frustration - constant leg kicking under the table. When we did break off in to group, the style of chairing also didn’t enable a balanced debate. This respondent also commented: “I do not directly work with patients and their families – perhaps the questionnaire questions need to assume that there will be more strategic/managers attending.

4. A strong ‘medical’ representation at the course. While this is useful, I would have preferred more Social Work presence, engaging with the Psycho-Spiritual issues which commonly with emerge with Patients and their families.

5. Really enjoyed the day, especially the discussion of case studies. Would have liked to have a bit more information of the reasons/background to differing beliefs around EOL/dying etc.

6. The panel was excellent and a good mix.
Organ donation issues would have been very helpful.
The content/syllabus of the health/rabbi course in New York would be very interesting to discuss. I felt at times the discussion was too general; it broadened to a general discussion of end of life issues rather than issues specific to Jewish/Muslim patients. At this point perhaps the Chairman of the panel could intervene and steer the discussion back to the objectives of the course. Martha is writing a PhD on this topic, it would have been immensely helpful to have her participate in the panel and learn from her knowledge. It was a thoroughly fascinating seminar; I was not distracted for a minute. I would love to be involved again in the future and if there is anything I could to
help please ask! Finally, of course, Ed Kessler had a brilliant 'real world' perspective which really added to the mix of views. Thanks again Ed I never fail to learn from you.

7. I am sure I will find the information etc. gained on the training useful when I work with a dying patient.

8. Refreshing to see that end of life issues are universal and there are so much common ground in the spiritual/religious issues that arise.

9. I did raise this on the original course feedback given to the day. I strongly feel organ donation should have been a specific topic of discussion. Donation is an issue not only for patients who die in ICU and A&E but also those in the community and hospices where the option of tissue donation exists.

10. It was a very helpful course.