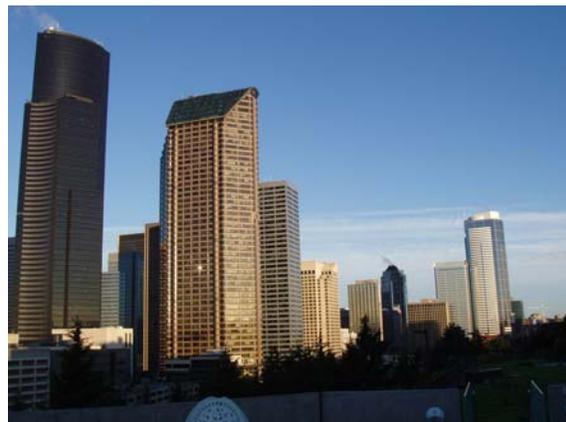


Physician-assisted suicide v Palliative care: a tale of two cities

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I always seem to get inspiration and renewed vitality by contact with this great novel land of yours which sticks up out of the Atlantic.

Winston Churchill

Executive Summary

1 Introduction

Proponents for the legalization of physician assisted suicide (PAS) argue that it has been legal in Oregon state since 1997 and that it works well. They maintain that palliative and hospice care can co-exist comfortably with the option for PAS.

My aim was to examine these claims, in two cities in the Northwest of America; Seattle where there is no legalized PAS and Portland where PAS is legal.

2 Aims of the Fellowship

To research the literature on Physician-assisted suicide (PAS)

To look at palliative and hospice care provision in Seattle and Portland

To identify why patients in Oregon choose PAS

To talk to researchers , ethicists and healthcare providers of end of life care in order to assess the relationship between hospice, palliative care and PAS.

To reflect on the ethical arguments around choice and autonomy

To determine if the Oregon experience should influence practice in the UK

3 Background

I am opposed to the legalization of euthanasia and PAS . I traveled on the Fellowship in the hope of having my own views challenged and to study end of life care in the USA.

4 Palliative Care and Hospice Care

Palliative care and Hospice care have evolved in different ways in the USA compared to those of the UK. Misunderstandings may result in defining hospice care, if it is assumed to be the same as specialist palliative care in the UK.

4.1 Hospice care

Hospice in the USA is community provision of care which is mainly social and nursing care supplementing the care by the family. There is a lack of specialist psychosocial care. Hospice care in Seattle and Portland takes place at the extreme end of life. 50% of patients who are referred to a hospice program die within 16 days. There was agreement that patients were referred to hospice too late in the course of their disease.

4.2 Palliative care

There is a lack of understanding of how palliative care relates to hospice care among healthcare professionals. Palliative care has evolved in a variety of ways even within the same city: three hospitals in Seattle have different patterns of palliative care.

4.2.1 Physician Orders for Life-Sustaining Treatment (POLST)

Over the past few years it has emerged that advance directives have drawbacks which hinder their effectiveness in ensuring appropriate end of life care. The POLST system, developed in Oregon, is an attempt to improve end of care by acting as a tool for communication about goals of care.

4.2.2 The image of palliative care

It is assumed that the palliative care team is only involved at the extreme end of the terminal phase of illness, so hospitals are disinclined to value such care. Indeed even where there are resources for palliative care there is often resistance from the attending physicians and surgeons to involve the palliative care team.

5 The American Health Care System.

I did not meet any healthcare professional in Seattle or Portland who was enthusiastic about the American health care system.

6 Education

I learned about educational initiatives in palliative care, based on the research being carried out in both cities. A doctor in Seattle has developed an innovative palliative care

module for teaching undergraduates. There is a paradox that these students may never have the chance to apply their training in a work setting. However, it is hoped that they may become agents for change.

7 Physician –assisted suicide

Physician –assisted suicide is sometimes referred to as hastened death in the States, but physician assisted suicide is a misnomer because it is not just the physician who is involved but family, pharmacists and nurses.

The option to have PAS is widely perceived as a safety net .However, hospitals in Oregon do not permit PAS on their premises. Hospice doctors do not sign lethal prescriptions.

8 The request for PAS

Of the 35,000 deaths per annum in Oregon, only about 30 people use PAS . Only 1 in 10 requesting PAS proceed as far as picking up the medication and of those only about half take it. This tiny group have been studied extensively: contrary to earlier assumptions they are not suffering terribly, they are not in pain and nor are they depressed rather they appear to have a need for control throughout their lives. They simply want to be able to choose the time of their death and prefer to avoid a violent suicide. However, many patients who initially ask about PAS change their mind.

9 Research

I talked to members of two research groups one in Seattle and the other in Portland. It was invaluable to be able to discuss their research , particularly their personal views about PAS and end of life care.

The Seattle group found that PAS requests may not persist and that the prominent concerns were not about pain but about loss of control and dignity. Yet doctors feel least comfortable when addressing existential suffering. Patients were looking for more than a prescription ; they sought a guide through the dying process.

10 Ethical Considerations

Much has been written about the individual's choice and the importance of autonomy but little about the social consequences of legalizing PAS . In the complex process of dying it is questionable whether fully autonomous choice is a realistic possibility. There is a need to develop more sophisticated models of autonomy which take account of the social nature of dying and to evaluate the moral agency of the individual who is dying and of the many carers .

11 Lessons Learned from the Fellowship

To research the literature on Physician-assisted suicide (PAS)

I have had the time to not only research the literature but to discuss the papers with the authors.

To look at palliative and hospice care provision in Seattle and Portland

I have gained a clearer idea of how the health care system operates in the USA. I learned that health is a market commodity which affects the provision of all types of care, doctors and nurses in the USA are trying to deliver the best possible care given the restrictions of their health care system. I found that there are inspirational doctors ,nurses, psychologists ,social workers, ethicists and researchers who are pioneering ways of improving end of life care in Oregon and Washington state.

I experienced a gaze aversion reaction by many Americans to the inevitability of death and dying. It is almost as if cancer were not a lethal illness and if enough treatment is provided , you can live forever. I saw that there is a large imbalance in favour of active treatments even in the most futile situations. I was also aware of a lack of continuity of care in the USA system, whether in hospital or the community.

I found confusion regarding the definition of palliative care and hospice care ; both palliative care and hospice care in the USA tend to be given at the very end of life. While I appreciate that the involvement of palliative care in intensive care may be peculiar to this region ,in the UK intensive care is more restricted .

I was interested to see interdisciplinary specialist palliative care in its early development

in parts of the Northwest United States. There are no specialist in-patient units for complex cases and medical involvement in the community is patchy.

To identify why patients in Oregon choose PAS

I learned that the patients who choose and carry out PAS are not suffering, they are a tiny group who simply seek control as to when their life will end. They are independent and have no interest in receiving palliative or hospice care. The main benefit of the PAS legislation in Oregon appears to be that it offers patients a way out if things get too bad. The need for this safety net is fuelled by the fundamental lack of trust that these patients have in the medical health care system. I found that there are still many physicians in Oregon who object to PAS.

To talk to researchers , ethicists and healthcare providers of end of life care

I enjoyed discussing research being conducted on dying patients and their families which has refuted many of the assumptions made about physician-assisted suicide.

To assess the relationship between hospice , palliative care and PAS.

I was aware that there has been improvement in end of life care in Oregon, but experience in the UK has shown that improvements in palliative care can occur independently of legalization of PAS. I felt that hospice programs sit uneasily with PAS, hospice staff want to support patients and families but do not want to be involved in PAS. No hospital in Oregon allows PAS to be carried out within their premises or by their doctors while they are working for them; very few doctors take part in PAS.

To reflect on the ethical arguments around choice and autonomy

The primacy of respect for autonomy is carried to an extreme in this region of the USA with less regard to issues of justice in health care. There is a need to develop new models of autonomy which take account of the social aspects of death and dying.

Oregonians are proud of their independent character and while many of them may be content to have the law permitting PAS, their values and beliefs are different from those of the majority of the UK.

To determine if the Oregon experience should influence practice in the UK

One of the motives for supporting legalized PAS is an urge to prevent violent suicide which is extremely rare in this patient group in the UK. There are links between palliative care, ethics and the teaching of communication skills in this part of the USA which could be beneficial if applied to health care education in the UK.

I remain convinced that there are better ways of helping patients to feel safe rather than legalizing PAS. The problems faced by the tiny group requesting PAS need be addressed in a different way .

12 Recommendations : A Fellowship for the Future

Forming a National Consensus Group

Retaining current legislation prohibiting PAS in the UK

Developing links between palliative care ethics and communication skills.

Researching the needs of those who seek control and who ask for PAS despite the availability of good palliative care.

Trust and the safety net

End of life care planning

Continuity of Care

Autonomy, Choice and Fellowship

Physician-assisted suicide v Palliative care: a tale of two cities

1 Introduction

As chair of the ethics committee of the Association for Palliative Medicine UK, I have been involved in the euthanasia and physician-assisted suicide (PAS) debate over the past three years. During this time, Lord Joffe has made three attempts to legalize “assisted dying” in the UK. After the second Bill, in 2005 , a House of Lords Select Committee was formed to consider the evidence for and against euthanasia and PAS. After six months of deliberation they were unable to reach a consensus but they did make recommendations that any future legislation would need to address. In particular they were unconvinced that there were sufficient safeguards in the proposed legislation.

In May 2006, Lord Joffe re-introduced his Bill , dropping euthanasia but legalizing

PAS . It was defeated in the House of Lords; because of the lack of safeguards and clear opposition from the medical profession. Lord Joffe is determined to bring this issue back to parliament in the next session. Physician-assisted suicide is therefore an important issue for patients, their families, healthcare professionals and our society. Proponents for the legalization of PAS argue that it has been legal in Oregon state since 1997 and that it works well. They maintain that palliative and hospice care can co-exist comfortably with the option for PAS. My aim was to examine these claims in two cities in the Northwest of America; Seattle where there is no legalized PAS and Portland where PAS is legal.

2 Aims of the Fellowship

To research the literature on Physician-assisted suicide (PAS)

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3 Background

My itinerary is in Appendix A. I selected contacts to draw from a wide spectrum of opinion. I also arranged to meet leading researchers in the field of ethics and end of life care. The interviews lasted from one hour to three hours and were taped and later transcribed. I have destroyed the tapes to preserve confidentiality. I assured the interviewees that their opinions would be reported anonymously to ensure that they were frank in their views. The taped interviews were transcribed and from these certain themes emerged. Quotations from the tapes appear in italics .The views expressed in this report represent a snapshot of a tiny part of the USA. They may not represent end of life care in other parts of the USA. I am opposed to the legalisation of euthanasia and PAS and went on the Fellowship in the hope of having my own views challenged and having an opportunity to study end of life care in the USA.

4 Palliative Care and Hospice Care

Palliative care and Hospice care have evolved in very different ways in the USA compared to the UK. Misunderstandings may result if it is assumed that if patients are receiving “hospice” in the USA, that this is the same as specialist palliative care or hospice care in the UK.

4.1 Hospice care

Hospice care in the USA is defined by the Medicare reimbursement system which applies to “eligible” patients. To be “eligible” a patient must be over 65 years old and have a prognosis of less than six months. Furthermore the patient must agree to waive any other active treatment options such as chemotherapy or radiotherapy. The reimbursement is paid on a per diem basis and this amount (around \$150) has to cover all home nursing, social support, drugs and medical input. Since the average length of time a patient is in a hospice program is around 18 days it can be a severe financial strain on the hospice providers. However, patients with lower levels of need and who stay longer on the hospice program attract the same daily allowance so hospice providers can recoup some costs on these patients.

Hospice in the USA is a largely a community provision of care which is mainly social and nursing care supplementing the care by the family. There is a lack of specialist psychosocial care.

“ We are dismal in this country with psychosocial care ..we don’t have social workers integrated into out patient care”.

In an Oregon hospice program there was a social worker who had considerable input into patient and family care but little evidence of specialist psychology input.

Medical directors of hospice programs vary in their involvement ; some review the cases at weekly multidisciplinary meetings whilst others do home visits in complex situations.

Multidisciplinary Meeting

I attended a MDM at a hospice where the doctor read out the diagnosis, a clinical

care manager listed the problems identified and then there was discussion from the social worker, nurse and spiritual adviser. In two hours twelve new patients, twelve patients for recertification as eligible for hospice and eight review patients were discussed. The data from the meeting was directly put onto computer as all the participants had laptops.

Since there is no out of hours night care at home, it is not possible to sustain dying patients living alone at home. The hospice is not a specialist palliative care inpatient facility, if patients require admission at the end of life they tend to go into nursing homes. Hospice care in Seattle and Portland is provided at the end of the terminal phase of illness, there was agreement that patients were referred to hospice too late in the course of their disease. Another problem is that, unlike the UK, there is no infrastructure of general palliative care provided by primary care teams. Providing continuity of care in this situation is challenging.

“Continuity is not there because the next visit is with someone else.”

“When the patient goes into the hospice program they have to transfer to the hospice physician. In theory continuity can happen but in practice it doesn’t.”

A physician in Seattle commented *“Often when their oncologist knows that they in a hospice program they will sign them off..the hospice medical director may not see them..the family doctor does not tend to visit..its not billable..the patient feels abandoned”*

Patients under the age of 65 do not receive Medicare, neither do they all have their own insurance. Those who do have insurance may find that the cover does not extend to hospice benefit. I heard of cases where patients waited until the last moment so that they could afford to pay for their care.

Case History

“A teacher aged 57 with breast cancer had insurance for hospice which covered one week of input. Her health insurance had a 10% charge which she had to pay.. this

amounted to \$75,000 for her chemotherapy (Total bill for \$750,000) and it wasn't over...so she was waiting until the last minute to utilize hospice care"

Most eligible patients do not have access to the benefits of the hospice program because they are referred too late: 50% of patients dying within 16 days of referral.

In Oregon dying patients want where possible to remain at home . The state has one of the highest percentages of home deaths with 50% of patients dying at home.

(National figure for USA 25%).

Financial concerns are a major consideration of medical care in the USA: one high cost patient can bankrupt a hospice provider . It is therefore difficult for smaller hospice providers to make a profit where larger organizations benefit from an economy of scale. As hospice providers are part of a market economy, competition inevitably arises between providers in the same city.

4.2 Palliative care

“ Lots of folks won't admit they have six months ..prognostication is difficult ..so palliative care developed to meet their needs”

A Physician

“There are pockets of expertise but oceans of ignorance”

A Nurse

In contrast to Hospice care , Palliative care is seen as something which can apply earlier than the six month time limit but there is a lack of understanding of how palliative care relates to hospice care.

“Most people approaching the end of their lives try to live the best life then can in difficult circumstances. Palliative care teams can help patients talk about the challenges they face and also point out that there will still be opportunities.”

Palliative care has evolved in a variety of ways even within the same city. In Seattle in three hospitals there are very different patterns of palliative care.

In the University of Washington Hospital the palliative care team is physician led and works to educate other health care professionals towards best practice through a consult service in the hospital. The physician plans to institutionalize palliative care making it part of mainstream medicine. Palliative care doctors are involved in advising on pain and symptom control but do not write drug charts. They play a role in end of life care in family meetings.

Case History Family meeting

A 50 yr old man with advanced lung cancer had chemotherapy which had failed. He had a further course of another drug but then developed leukaemia. He was confused, in pain and wanted to go home. The chest physician called a family meeting with the palliative care doctor. The patient was in a side room with his wife , two daughters, brother, mother , a friend and granddaughter. Others in the room included a social worker nurse and medical student. The palliative care physician began with

introductions and then explored the goals of care with the family, as the patient was too distressed.

It was clear that some members of the family were still hoping for a miracle. The physician then ascertained that the patient had always expressed a hope to be at home and identified which family members would be the key care providers. He then outlined the role of the social worker in arranging hospice support at home. He gave opportunities for the family to ask questions and they agreed that further treatments in hospital would be inappropriate and were grateful that their relative could come home.

An aim for the service is to achieve earlier referrals. The palliative care team also provides continuity for patients in an environment where treating teams may change frequently and psychosocial care is fragmented. They found that care plans and advance directives enhanced patient care.

A physician commented on the problem for doctors and patients in facing uncertainty. *“When I first started in medicine uncertainty was my enemy. The more I do palliative care, I realize that uncertainty is my friend. If anything can happen so hope can be maintained”*



In Harborview Hospital the palliative care service has been set up by a nurse practitioner who runs the service single-handed apart from some holiday cover. As the service started with a research grant, up to 40% of referrals come from intensive care . Palliative care has remained hospital based because it is not funded and only large organizations can stand this loss of income.

In the intensive care setting the palliative care nurse helps in family meetings to discuss withdrawal of treatments and helping families come to terms with the situation. This hospital has seven intensive care units and

caters for some patients with severe stroke, advanced cancer or other advanced disease with multi-organ failure; who would not be admitted to intensive care in the UK. Part of the palliative care role was to *“bring humanity into the ICU , enable them to focus more on the patient and less on the monitor”*.

The work of the specialist nurse is concerned with sudden illness, crisis intervention, establishing the goals of care. The culture of the organization is such that;

“It’s almost a failure if they have to consult you for pain and symptom management”.

Patients’ access to palliative care is controlled by treating physicians . The service here has developed because the physicians and surgeons do not perceive the nurse as a threat. Family meetings are held to establish goals of care

“we need to meet the family in advance otherwise we are throwing the family into a decision making role while they are still in crisis..we need to know the person “

Sometimes these meetings were trying to deal with all the communication and emotional work in a single session.

There are cultural differences in patient expectations. For some patients it is

“foreign to them not to know that what the physician says goes”

African –Americans are often reluctant to access palliative care and hospice programs. Historically there is a lack of trust in doctors perhaps exacerbated by the appalling Tuskegee Syphilis study which ran from 1932 and lasted forty years. The study looked at the effects of untreated syphilis on African –Americans . None of the 399 participants consented and they were misled about the study. When effective treatment for syphilis became available they were not given penicillin.(King PA, Wolf LE 1998)

Palliative care is sometimes requested because nurses become frustrated with “over treatment “.There was some lack of understanding around the specialist skill set of palliative care. Palliative care involvement may then appear critical of the treating team’s care .There was no admitting service for specialist palliative care and

therefore no opportunity to manage the most complex palliative care problems.

In the Veterans Administration Hospital, there is a multidisciplinary team which



operates in the hospital and provides a system which is closer to the UK model of a hospital support team. The management decided that every Veterans Administration hospital had to have a palliative care service but did not provide the extra funding .”.

The focus here was on inpatients and the hope was that palliative care could extend into out patient practice. They appreciated that some patients need experienced specialist palliative

care ,*“some of these need some grey hair and some experience”*



In Portland , the Veterans Medical Center has a multidisciplinary palliative care team with medical, nursing, psychology ,social work and psychiatric in put. I attended a multidisciplinary team meeting and met highly skilled palliative care specialists. There was a wide ranging discussion around medical, social, psychological and spiritual issues for each patient. This team works with patients in the Veterans Center and has no outpatient or community

remit. Indeed families of the veterans are not covered by this Center.

In the Oregon Health Sciences University hospital there is both specialist medical palliative care and an ethicist in the team. Ethics consults are a feature of hospitals in the USA and do not feature at all in the UK. Palliative care in hospital was described by a doctor as ;

“SWAT team palliative care”.

The Oregon team were involved in developing an innovative advance directive known as the Physicians Orders for Life- Sustaining Treatment (POLST)

Physician Orders for Life-Sustaining Treatment (POLST)

Advanced directives were originally developed as a means for people to have control over their end of life care when they were no longer able to make decisions themselves. They originated as a response to the perceived excessive use of aggressive life-prolonging treatments. However from a patient's perspective their primary aim is to prepare for death and dying, thus achieving a sense of control and relieving the burden on the family .Over the past few years it has emerged that advance directives have many drawbacks which hinder their effectiveness in ensuring appropriate end of life care: the completion rate is about 30% and they focus on treatment refusal rather than understanding the patient's values and goals. They tend to be vague and may inhibit discussion on end of life planning.

The POLST form, developed in Oregon, is an attempt to improve end of life care by acting as a tool for communication about goals of care. As well as acting as a basis for conversations between doctors, patients and their families it is intended that it should follow the patient into any setting where care is provided. It is an attempt to individualise planning, but it does suffer the limitation of all tick box approaches. It may confuse the patient with too many issues. There should be frequent review of treatment plans as the disease progresses. The POLST form is not a substitute for sensitive communication as it can be interpreted by people in different ways. It is best seen as informative rather than binding since people can change their minds or the situation can change. Perhaps what is needed is not just decisions on specific choices but rather to map a personal approach to dying. Determining the place of care and limits of life sustaining treatment is an important way of relieving the burden on the family . Planning needs to involve the family and friends and current approaches in bioethics neglects this social element of care . It is the discussion around advance planning which is more important than the forms. The forms however can act as a tool and give a framework for the discussions.

“It is better to plan care at an earlier stage since it may be easier for patients to talk about end of life issues earlier when it's a bit abstract”.

A sample form is included in Appendix B

4.2.2 The image of palliative care

It is against the instincts of many teaching hospitals in the USA to consider palliative care as it is associated with impending death or even promoting death. Even where there are resources for palliative care there is often resistance from the attending physicians to involve the palliative care team. After one episode of the palliative care team's involvement a surgeon was quoted as saying :

"You didn't do anything to make my life harder"

another said , about the palliative care team :

"I hate to have you guys involved ,but you know. .you were actually helpful"

There was agreement that psychosocial care was a neglected area in the hospital setting. There is a circle of aggressive technological care with the doctors pushing and the patients asking for more treatment, the picture is complicated because profit is involved.



Most of the advances in medicine result not in the cure of illness but in the prolongation of life in patients with chronic illness. In such an environment palliative care can be an unwelcome presence :

“because we are going in the opposite direction to everyone else in the hospital”

A physician felt that *“palliative care is often viewed as wimpier..mushier..not as rigorous”*

5 The American Health Care System.

I did not meet a single healthcare professional in Seattle or Portland who was enthusiastic about the American health care system.

“our system here is lousy..really bad...its just appalling...no political will to change it”

Whilst there are undoubtedly problems with our NHS, the problems in the USA are so different that it is difficult to make direct comparisons of palliative care provision.

The United States spends twice as much on healthcare as other industrialised countries in relation to gross domestic product. There is a gap between rich and poor, serious illness can result in poverty for those trying to meet their healthcare bills. 60% of all credit card debt in the USA is related to health care payment. Over 47 million Americans have no health care insurance cover.

Palliative care can only progress in the USA if it can compete in the market place. Some hospital palliative care services have to demonstrate that their involvement in patient care saves money by earlier discharge from hospital.

“In a capitated health care system we are challenged ; show us what you can do for us. If we get them out of ICU earlier this is beneficial...one reason why we have got into this area”

The problem is compounded by the fact that the culture demands continued rigorous treatment. Nobody confronts end of life care until the last moment. Difficulties can arise

when the family wish to stop treatment but the physicians want to continue in the hope of a miracle. Sometimes the palliative care team can be perceived by the primary treating team as advocating hastened death, they appear to believe that by involving palliative care the patient's life will be shortened. The evidence, however, indicates that good palliative care is linked to longer survival.

One consequence of the competitive market system of health care is that some patients are worried that they will be undertreated by being, denied diagnostic tests or chemotherapy or life-prolonging surgery. This may be one factor to explain why so few African-Americans have advance directives. Historically, as discussed earlier, they have good reasons to distrust doctors.

6 Education

Educational initiatives in palliative care were carried out in both cities. One doctor commented on the lack of training in communication skills in the undergraduate curriculum:

“students are taught to go in and talk to the patient and get a code status...whether the patient wants to be resuscitated that's what they think this talk is....not...

What's important to you?,

What do you want to accomplish in the time?

What do you consider to be a good death or a bad death?

Have you seen people in situations which you don't want to be in?”

Appropriate symptom control was always an educational challenge :

“ Low opioid prescribing continues to be an issue as you get new staff you are starting from zero.”

Some felt that:

“if the law was changed back in Oregon the benefits would continue in palliative care education”

A doctor in Seattle has also developed an innovative palliative care teaching module for undergraduates. There is a paradox that these students may never have the chance to apply their training in a work setting. However, it is hoped that they may become agents for change.

The students learn when it becomes appropriate to have a discussion about the patient's goals for their end of life care. As a rough guide they ask themselves "Would I be surprised if this patient died in the next six months?" if the answer is "No", then they are taught that they should have a discussion along the lines of "What might happen if things do not go well".

"We spend seven years teaching medical students that patients are all the same. We spend the rest of our careers learning that they are all different".

7 Physician –assisted suicide

I had numerous descriptions of cases of PAS. I include one that a doctor claimed went well and another which illustrates just how badly it can go wrong:

Case History

A young man moved specifically here because Oregon had the law. He had a strong belief in an after life. He decided the day, took the medication and died peacefully. The hospice nurse knew the day but was not involved. She came to the house after his death and supported the family

Case History

A patient with a cancer had a friend who was a doctor. This friend told him that it was going to be a painful way to die and advised him to take advantage of the PAS law. The hospice staff felt he was not ready to die and were concerned that he may have bypassed some of the legal hoops. The family were not happy and everybody involved was uneasy. After taking the lethal prescription the patient didn't die quickly. The family were upset..why hasn't he died?. The wife said she had to leave, she could not cope with the situation. The volunteers from a pro PAS organization found two men who knew nothing

about nursing care to sit with the patient until he died the next morning.

The wife became profoundly depressed and attempted to commit suicide herself.

Physician assisted suicide (PAS) was sometimes referred to as hastened death. Physician assisted suicide is a misnomer because it is not just the physician who is involved but family, pharmacists and nurses.

There were different opinions amongst physicians; some felt that the lines between terminal sedation, PAS and euthanasia were blurred;

“I am not an advocate for hastened death but I have done it ...I can make myself feel better but it is often very grey when you look at it with a clear eye”.

Death with Dignity legislation was first raised in Washington State and defeated largely because the physicians took an active stance against it. In Washington state there was much resistance to PAS ;

“they don’t want to do it, don’t want to abandon their patient, it goes against the grain of how people are trained. There is a fundamental lack of continuity of care so they can’t claim to know the patient that well. Its morally ambiguous.”

“Euthanasia will never be sanctioned in the USA, but PAS could be”

It was felt in Seattle that in Oregon families receive more psychosocial support because the law exists but that in Washington state there is no support for families or patients seeking a hastened death because it is illegal. Others think that it is possible that harms can result from not having a choice for PAS:

“ You are not looking at the harm which results when PAS is not done” “if it is illegal it is not going to stop the practice.”

“None of the arguments against PAS convince me. Make it harder...that’s OK...look at the harms to those who seek it and can’t have it compared to the wider harms to society”.

An ethicist felt that we should keep the option for PAS on the table:

“We want to manage death on their terms and in the vast majority of case palliative care does that..but we need to recognize that there are some patients we can’t help”

The option to have PAS was widely perceived as a safety net:

“its an insurance policy. I have a way out. I need to be strong so I can fight..and be strong”

“ I don’t think that these people want to die ...they want an insurance”

“Is it better it happens in secret? You guys are light years ahead of us. I think it should be rare, I want to prevent a violent suicide”

The urge to prevent violent suicide was graphically illustrated by a sad case;

“Horrible violent suicides.. discovering a husband’s headless body in the garden..the legacy left behind for the family is horrible”

Nurses vary in their views on PAS; about a third are opposed and about 10% would seek not to be involved with that patient in any capacity. Doctors attend about a third of the time mainly to assess competency, some do not give the medication until the patient is ready to take it. The patient is unwilling for the doctor to implement PAS ,they wish to carry it out for themselves , sometimes they do not wish the doctor to be present.

Hospitals in Oregon do not permit PAS on their premises. However, there is no problem for a patient in finding a doctor who will carry out PAS. Most commonly their own doctor will not agree but refers the patient to a hospice program. The hospice doctors do not sign lethal prescriptions but may refer the patient to another doctor who is willing to do so or patients usually contact the organization Compassion & Choices Oregon which has a list of doctors who are willing to carry out PAS. This organization strongly supports the legalization of PAS and provides information and advice to those interested in PAS. They also have volunteers who may be with the patient when they take the lethal medication. This organization is involved in about 75% of the cases of PAS in Oregon.

Compassion & Choices Oregon maintain that PAS deaths are not “suicide” but “hastened death”. The death certificate in a case of PAS certifies natural causes as the cause of death and does not mention PAS.

A Compassion & Choices representative emphasized that he felt :

“even if no one used the law.. it would still be worth its weight in gold, for the comfort it provides.”

He felt that patients are not requesting PAS because they are suffering but because they are choosing not to have the experience of dying from their underlying disease.

“For this small group who choose to take the medicine I am not here to judge whether it’s right or wrong. I make sure the option is available”

In one hospice program, they have had 28 cases of PAS since the legislation was in force. In 23 of the cases same doctor was involved. He is known as a strong advocate for patient choice and does offer all the alternatives. Only a few doctors participate perhaps because a significant proportion of Oregonians do not support PAS.

There can be problems in leaving the lethal medication at home. In one case where there was doubt as to whether the patient was competent when he eventually took the medication and it may have been administered by the family. The question of administration was a delicate one, a patient even had a PEG feeding tube inserted solely to allow him to have PAS.

To qualify for the Oregon PAS legislation the patient must be a resident in the State. Any citizen of the USA can be a resident of a state if they declare that it is their intent to reside in that state permanently.

In Seattle a physician expressed his view;

“If you offer good quality palliative care ,PAS is very rarely an issue. Offering PAS in absence of good palliative care is a travesty”

8 *The request for PAS*

“In America getting old is sin enough, ...dying is unspeakable.”

A Physician

The request for PAS is an opportunity to explore the reasons for the request. Patients often receive care from a number of doctors who may not communicate with each other.

“I had a patient with lung cancer, she went to another physician and got a prescription. I found out later from the family that she had done PAS.”

Only about 30 people in Oregon use PAS each year of the 35,000 deaths per annum. This tiny group have been studied extensively and contrary to earlier assumptions they are not suffering terribly, they are not in pain and nor are they depressed. This group of people have always had a strong need for control throughout their lives. They simply want to be able to choose the time of their death and prefer to avoid a violent suicide. Research in Oregon suggests that these hyper independent people often have a history of childhood deprivation and have had to learn to survive on their own. They dislike losing control and having to depend on others so palliative care has no appeal for them. They may not even seek support from their family who may wish to care for their loved one. Paradoxically doctors also share some of these characteristics of wanting to be in control.

“It is a measure of their determination that they go through so much work to achieve PAS while they are ill.”

”One woman who was contemplating PAS went to buy apple sauce to mix with the tablets to make them more palatable. Her husband saw her in the supermarket studying the label on the jar to see if there were any additives or colourings”.

Families may be placed in an ambiguous position and some have the fear:

“am I encouraging him to die by supporting his decision?”

Family members might not agree with PAS but feel that :

“out of respect for my mother I go along with it”.

One perceived positive element of the PAS request is that there is no longer room for denial in these families once the request is made:

“the elephant is not in the room”

Some felt that the size of the problem was too small to justify creating a national policy to cater for this tiny group of people who need control.

There is a whole spectrum of involvement even among those opposed, from being out of the room when it happened, to being there to support the patient while they took the medication, to mixing the tablets in a liquid to make it palatable to helping to administer the lethal prescription.

“If family members are helping we are not hearing about it.. It’s possible to get a lethal prescription without the hospice knowing about it.. they wouldn’t want to offend the hospice nurse”

Nurses gave differing descriptions of PAS deaths, some said it was a pretty death with the majority of family members thinking it was wonderful. Others described the patient screening out family members who would object. A nurse spoke of supporting a son mixing the medicine for his mother and after she took it he was sobbing uncontrollably. Of the patients who first request PAS only 1 in 10 get as far as getting the medication and of those only about half take it.

“So many more talk about PAS than do it” .

There is a strong feeling that :

“they have an out” .

Hospice staff were not entirely comfortable with their position :

“we are all glad when they don’t do it.”

At one meeting which I attended there was a bleak pause as a nurse excused herself to attend a patient, whom she had never met, who was going to commit suicide at 2 pm.

Many patients who initially ask about PAS change their mind :

“If you come right at PAS they kind of hang on to it more, but if you nick at the edges from hospice, help to make them feel in control and show how I respect you as a person, then many don’t go down that route..90% go for hospice”

The most common response from physicians to a request for PAS is referral to hospice. Hospice program staff felt that pain control was not an issue for those seeking PAS.

“They don’t want to take the chance of a poor quality of life”.

Whilst many patients gain comfort from the safety net of the legislation permitting PAS, others can be traumatized by insensitive communication:

Case History

One patient with motor neurone disease(ALS) was given the diagnosis and at the same time was informed by the doctor of the availability of PAS. “You have ALS, ..this is awful,you should consider PAS”

The patient felt devastated.

Most hospice staff felt that it was wrong to deny patients who had chosen PAS the same emotional care as any other patients. One comment was that it was difficult when it first became law but was more acceptable now:

“After the first year or two it became normal..it wasn’t a big deal.”

Hospice teams identified which patients had requested PAS and regularly reviewed whether they had changed their minds.

If a team member did not support PAS they could opt out of the care of the patient. One team said they had never seen bad deaths from PAS and had only one patient that took 24 hours to die. Some patients practice to make sure that they can swallow the 200ml of liquid necessary to dissolve the pills.

Some felt that it was not a just law because it was not available for those who could not swallow .

“A patient with ALS (motor neurone disease) may have to suffer for years and does not have this choice whereas a cancer patient who is going to be dead in six months anyway and may not be suffering, does have this choice”

A patient may have no suffering but once they have their six month prognosis they can start the process for PAS. The patient can come to the hospice as part of the process and with the sole intention of committing suicide, wait the required 15 days then take the lethal medication. It is assumed that these patients are not clinically depressed and there is no psychiatric assessment.

One ethicist was concerned that the harms of closet PAS outweigh the hypothetical harms of legalized PAS. There is an urge to prevent violent suicide either by using a car or a gun. It was hard to know whether more palliative care would have made a difference. There was concern that by keeping PAS illegal that it would inhibit communication around death and dying. However , in the UK, palliative care specialists feel protected by the legislation which permits them to raise questions about death and dying without fear that the patient might think they are suggesting PAS as an option.

Research has found that patients who carried out PAS could be divided into three groups according to how far their disease had progressed.

1. Those who were clearly dying and were within days of death. It appears that the issue for them is one of control. These cases were not so distressing to the researcher.

2. A group who probably had about few weeks to live.
“ They had no unfinished business, they were just worn out.”
They just felt that they were not dying fast enough.

3. A small group who hastened their death despite having the potential to survive much longer. The researcher describes her ambivalent feelings about this group :

“ When we started to work back it all became more uncomfortable and felt like it was rather like a preemptive strike...very hard....its hard to say that you know better than them...all three of them had personality twists.. they had become self reliant ,narcissistic and manipulated everyone around them...it was all about them...do you say they are incompetent...areas of sympathy in their story...these are unconventional people...what do you do?”

“They had carefully thought through what would happen to them..we have had a full life and done the things we want to do....the things ahead I don’t want..I don’t know why I have to because you tell me I have to go through it. The effect on family, community..it’s not easy to challenge people who are dying..they don’t consider other people.”

In Seattle a nurse commented :

“We do see people who request PAS or hastened death. The discussion follows to see if we can meet some underlying unmet need..then we may discuss palliative sedation if that seem s appropriate.”

They said that palliative sedation was rarely necessary.

9 Research

I talked with members of two research groups one in Seattle and the other in Portland. It was invaluable to be able to discuss their research and explore their own feelings about PAS and end of life care.

Seattle group (PAS illegal)

Most previous research on clinical responses to PAS requests have used data obtained from clinicians . The Seattle group studied 35 patients who were seriously considering PAS ; 12 prospectively and 23 retrospectively.

Three themes emerged that were valued by patients and their families:

Openness to discussions about PAS

Clinicians' expertise in dealing with dying process

Maintenance of a therapeutic relationship (even when the clinician and patient disagree about PAS)

It is interesting that this group also found that PAS requests may not persist and that the most prominent concerns were about non physical aspects of dying, loss of control and dignity. Yet doctors feel least comfortable when addressing existential suffering. Clinicians who deal obliquely with PAS requests may miss the chance to fully evaluate and understand the issues underling the request.

Patients were looking for more than a prescription; they sought a guide through the dying process.

They suggest that clinicians should respond to a request for PAS by using the guidelines

Address the PAS request explicitly and openly

Ask about what kind of death the patient would like to have

After understanding the patient's wishes and expectations, offer to discuss how dying could be managed.

Check the patient's perception "What are you taking away from our talk today?"

The process of building a therapeutic relationship is more important than providing a lethal prescription

Monitor yourself for over or under involvement in the doctor –patient relationship

Some researchers looked at the skills required by physicians in providing end of life care they suggest 12 domains of skills (Curtis JR et al, 2001)

Accessibility &Continuity

Team co-ordination &Communication

Communication with patients

Patient education

Inclusion &recognition of family

Competence including knowing when to stop

Pain &Symptom management

Emotional support

Personalisation

Attention to patient values

Respect and humility

Support of patient decision-making within these domains.

Family members may have different moral values to those of the patient requesting PAS. Families have multiple needs but little preparation is made for their role in the care. Where hastened death is illegal there are even fewer resources to support families in their role as witness to and sometimes facilitators of a hastened death. Patients and families have the added tasks of negotiating with physicians for prescriptions for lethal medications. They also were concerned to minimize the risk of investigating the death. They found in their series of 35 patients that 6 families encountered problems related to the medication during the dying process. In 2 cases the patient took over 11 hours to die and in 4 cases the patient woke up. Most families, however, were able to face issues of dying and make plans for the event but lack of professional support left them unprepared for adverse endings. They often felt responsible if the patient woke up and those families who experienced complications had difficulty adjusting to their loss. They also had worries about legal consequences. The main motivating factors for an interest in hastened death were illness related

experiences, issues of loss of sense of self and control and fears of the future. No patients met the criteria for a major depression episode. (E Vig et al)

The results from this study show that, just as in Oregon, it is the patients who are keen to be control who seek PAS. Lack of palliative care was not an issue for them.

Portland Group (PAS Legal)

Ganzini and her team have been concerned with exploring the views of healthcare professionals on PAS. Psychiatrists in Oregon were divided in their belief about the ethical permissibility of PAS. Only 6% felt very confident that in a single evaluation they could adequately assess whether a psychiatric disorder was impairing the judgment of a patient requesting PAS (Ganzini L et al 1995). Only a minority of Oregon Physicians were willing to provide lethal prescriptions (73 out of 2094 respondents).(Ganzini et al 2001)

Oregon physicians described patients requesting PAS as having strong and vivid personalities characterized by determination and inflexibility . (Ganzini L et al 2003) Most hospice social workers and nurses in Oregon do not believe that assisted suicide and hospice enrolment are mutually exclusive alternatives. 48% of the Nurses supported PAS and 72% of social workers supported PAS (Miller LL et al 2004) In another study 1 in 10 cancer patients expressed a serious interest in obtaining a lethal prescription at the initial evaluation; though the number of patients maintaining interest in PAS varied. Fewer than half of these patients discussed the issue with their oncologist. Of the 161 participants in the study only two ultimately made an explicit request for PAS , one of whom never indicated interest in PAS on any study assessment. (Ganzini L et al 2006) This study was the first to measure satisfaction with medical care, and found that dissatisfaction with care was associated with interest in PAS . Exploring specific causes of this dissatisfactions would be key to developing interventions. (Ganzini L et al 2006)

The researchers found that many patients with serious interest in PAS do not discuss this with their doctors or any other person. Clinicians in Oregon have been advised not to initiate discussions about PAS as there are concerns that patients may

misinterpret enquires, believing the physician is promoting PAS. (Ganzini L et al 2006). It is difficult for the physician to explore the patients deepest feelings if he/she cannot ask whether the patient has contemplated suicide. In contrast the current UK law is helpful in that it gives doctors the freedom to raise these issues without any fear that that they are misunderstood as veiled suggestions of PAS .

A reluctance to discuss these issues may leave the patient struggling in isolation. Expressing an interest in PAS does not seem to predict actual requests , but it does indicate psychosocial distress. (Ganzini L et al 2006)

10 Ethical Considerations

Those arguing for PAS justify their view by suggesting that it offers greater autonomy for the individual who they feel has a right to choose the time and manner of their death. The American legal system in Oregon, values and exalts individual autonomy; the right to choose PAS places a responsibility of physicians to help. A physician said:

“Americans are drunk on autonomy”

another ethicist referred to :

“The Great God Autonomy”.

There are cultural issues to explain why Oregon has legalized PAS.

“This is the West coast ..autonomy runs very strong.. self reliance”.

“ It’s not a coincidence that Oregon is the State that has this law. It is more libertarian than Washington”

“Oregon is the least churchd State in the USA” .

One ethicist reflected :

“trying to refocus on goals..what do these things mean to the patient? We in this culture will die..we forget that every single one of us will die..we fight this as though it was some strange terrible thing. We have at our disposal such incredible technology ..we are just not reflective enough in the individual case”

“What people expect here is unlimited..the culture is so different...they make insane choices”

Some felt that there was a clear ethical distinction between euthanasia and PAS on the grounds of differing moral agency. The doctor , pharmacist and nurse all know the purpose of the lethal prescription , but it is the patient who takes the medication. It is incidentally a misnomer to call it “physician” assisted suicide as it may be “assisted” by a number of different professionals and family members . Each of these have themselves differing moral agencies , since if the doctor did not write the script then the assisted suicide could not happen. The question arises “Are you a moral agent in the process if you are providing support?” It becomes difficult to tease out exactly who is involved. These are not merely abstract ethical arguments but have practical implications. Hospice programs allow their staff to support a patient who intends PAS but they do not permit their doctors to write lethal scripts. The hospice nurse if she is attending the patient will “take a walk around the block” while the patient takes the medication and returns to support the family. Many pharmacists are unwilling to dispense the prescriptions .

Where autonomy has a strong force in ethical argument the principle of justice is rarely discussed. In an argument promoting the principle of justice an individual’s autonomy is inevitably curtailed. Justice issues include the fact that for many people in the USA, there is no access to palliative care or to physicians skilled in pain and symptom control.

There has been much comment about the individual’s choice and the importance of autonomy but very little about the social consequences of legalizing PAS . In the complex process of dying it is questionable whether fully autonomous choice is a

realistic possibility. There needs to be a development of more sophisticated models of autonomy which take account of the social nature of dying and of evaluating the moral agency of the one who is dying and of the many others who will necessarily be involved if PAS is legalized.(Burt RA 2005). For proponents of PAS the autonomy of family members, doctors and nurses is viewed only as a problem insofar that it threatens to impinge upon the sick individual's autonomy.(Mann PS ,1998)

A dying person's sense of autonomy is fundamentally linked to their relationships to their family or friends. The feelings of the family inevitably affect the dying person's sense of their own agency. For example a wife's wish that her husband fight the disease may be the major concern or, conversely, if a spouse had recently died , the patient may not feel that they have any reason to live.(Mann PS 1998)

Mann argues that the complex social motivations for individual actions are ignored. She also contends that to understand individual agency , three potential dimensions of individual action have to be recognised; self-referential desires, feelings of responsibility and expectations of recognition. Her model of empowerment includes all three dimensions.(Mann PS 1998) As patients experience physical deterioration they often feel ambivalent about their choices and will be dependent on help from others. This dependency on others is unavoidable but denied by most of American society.

*“We are born dependent on others and we die dependent on others. Our dependence is as much a characteristic of what it is to be a person as is our capacity to make free choices”
Tallis R Saunders J Clin Med 2004:4 534-40*

As Derrida said , death is fundamentally confusing and paradoxical . Our sense of being in control at the end of our life has as much to do with our extreme dependency and with our sense of uncertainty in relation to the approach of our death as it does with an aggressive medical establishment denying our wishes .(cited in Mann PS 1998)

Mann warns that there is a risk if PAS is legalized “there will be social expectations for individuals to choose PAS as soon as their physical capabilities decline to a point where they become dependent upon other in an expensive inconvenient way” .(Mann PS 1998) There is strong evidence that this is no idle threat. In Oregon, it has now become appropriate to say that it is acceptable that individuals choose PAS to avoid uncertainty during the period of dying or to avoid dependency on others. In the words of one Oregonian..

“PAS is legal. It’s no big deal”.

In legalizing PAS Oregon have created a whole new set of relationships between dying patients, their families and the healthcare professionals. New end of life rituals have emerged around the process of dying by PAS. For instance, the choosing of a day and hour of one’s death, the presence of family, the absence of hospice staff . However the ultimate mystery of death remains; the abyss between life and death has not been altered by PAS. “Oregonians who accept PAS believe that there is a moment when the potentiality that philosophers identify with human life is properly extinguished by those who continue to live with potentiality somewhat longer” . (Mann PS 1998)

Lessons Learned from the Fellowship

To research the literature on Physician-assisted suicide (PAS)

I have had the time to not only research the literature but to discuss the papers with the authors.

To look at palliative and hospice care provision in Seattle and Portland

I have gained a clearer idea of how the health care system operates in the USA. I learned that health is a market commodity which affects the provision of all types of care, doctors and nurses in the USA are trying to deliver the best possible care given the restrictions of their health care system. I found that there are inspirational doctors, nurses, psychologists ,social workers, ethicists and researchers who are pioneering ways of improving end of life care in Oregon and Washington states.

I experienced a gaze aversion reaction by many Americans to the inevitability of death and dying. It is almost as if cancer were not a lethal illness and if enough treatment is provided , you can live forever. I saw that there is a large imbalance in favour of active treatments even in the most futile situations.

I was also aware of a lack of continuity of care in the USA system, whether in hospital or the community.

I found confusion regarding the definition of Palliative care and Hospice care ; both palliative care and hospice care in the USA tend to be given at the very end of life. While I appreciate that the involvement of palliative care in intensive care may be peculiar to this region ,in the UK intensive care is more restricted .

I was interested to see interdisciplinary specialist palliative care in its early development

in parts of the Northwest United States. There are no specialist in-patient units for complex cases and medical involvement in the community is patchy.

To identify why patients in Oregon choose PAS

I learned that the patients who choose and carry out PAS are not suffering, they are a tiny group who simply seek control as to when their life will end. They are independent and have no interest in receiving palliative or hospice care. The main benefit of the PAS legislation in Oregon appears to be that it offers patients a way out if things get too bad. The need for this safety net is fuelled by the fundamental lack of trust that these patients have in the medical health care system. I found that there are still many physicians in Oregon who object to PAS.

To talk to researchers , ethicists and healthcare providers of end of life care

I enjoyed discussing research being conducted on dying patients and their families which has refuted many of the assumptions made about physician-assisted suicide.

To assess the relationship between hospice , palliative care and PAS.

I was aware that there has been improvement in end of life care in Oregon, but experience in the UK has shown that improvements in palliative care can occur independently of legalization of PAS. I felt that hospice programs sit uneasily with PAS, hospice staff want to support patients and families but do not want to be involved in PAS. No hospital in Oregon allows PAS to be carried out within their premises or by their doctors while they are working for them; very few doctors take part in PAS.

To reflect on the ethical arguments around choice and autonomy

The primacy of respect for autonomy is carried to an extreme in this region of the USA with less regard to issues of justice in health care. There is a need to develop new models of autonomy which take account of the social aspects of death and dying.

Oregonians are proud of their independent character and while many of them may be content to have the law permitting PAS, their values and beliefs are different from those

of the majority of the UK.

To determine if the Oregon experience should influence practice in the UK

One of the motives for supporting legalized PAS is an urge to prevent violent suicide which is extremely rare in this patient group in the UK. There are links between palliative care, ethics and the teaching of communication skills in this part of the USA which could be beneficial if applied to health care education in the UK.

I remain convinced that there are better ways of helping patients to feel safe rather than legalizing PAS. The problems faced by the tiny group requesting PAS need be addressed in a different way .

Forming a National Consensus Group

The debate about PAS has become polarized. In Washington State a Washington End of Life Consensus-Coalition reflects the whole spectrum of opinion. This coalition has agreed to look at ways of improving the care of patients at the end of life. Their strategy has been to focus on consensus , the entire group must concur and if anyone is unwilling to support a new initiative they must justify their view. In this way differences are acknowledged although there will be areas where there will never be complete agreement . However, everyone has a common aim to improve the care of the dying.

“Whether we agree or disagree with the law we can work together on many issues we can improve communication .The extremes do the media, the majority in the center get on with improving palliative care”

In this way improvements in palliative care have occurred , probably quite independently of the legislation for PAS.

Retaining the current legislation prohibiting PAS in the UK

Professionals, patients and the public need the protection which the law affords if high standards of palliative care are to be made accessible to all. The Oregon experience of the legalization of PAS should act as a warning to legislators in the UK : PAS in Oregon has nothing to do with unbearable suffering, it is simply a mechanism, employed by a few independent patients who have a heightened need for control , to determine the timing of their death. Whatever arguments are advanced in the PAS debate it is clear that the Oregon experience cannot be claimed to be a valid reason for any change the existing law in the UK.

Developing links between palliative care ethics and communication skills.

There are innovative programs in the USA which could be adopted within the NHS to ensure that patients could meet doctors who are comfortable to discuss end of life issues.

(www.fammed.washington.edu/palliativecare/)

Researching the needs of those who seek control and who ask for PAS despite the availability of good palliative care.

The research from Seattle and Portland needs to be extended in the UK context. There is a need to know more about the issues surrounding the PAS request and to devise ways of helping these patients without putting others at risk.

Trust and the safety net

It is a sad reflection on the doctor patient relationship that a patient feels the need for legalization of PAS purely as reassurance that there is a way out. These fears need to be addressed and attention paid to both psychosocial and spiritual care . Doctors need to demonstrate to patients that medical technology will not be applied indiscriminately but with their consent .

End of life care planning

Tools such as the POLST may enable healthcare professionals to achieve the skills to discuss end of life care with patients and their families.

Continuity of Care

The NHS faces challenges in providing continuity of care . The market experience of the USA should be act as a warning to everyone in our society and encourage us to strive to preserve the principles of the NHS. In particular we need to preserve the network of primary care which surely is the best safety net of all.

Autonomy, Choice and Fellowship

New models of autonomy are required to reflect the dependency which exists at the end of life. Palliative care strives to respect the autonomy of the individual but needs to acknowledge that families ,friends ,staff and a wider society are all affected by the death of an individual. Choice cannot be unlimited. There has been a move away from the extremes of medical paternalism of the past and the consumerism of the present. Tomorrow we seek a Fellowship for the future.

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Thank you to my wife Pru

APPENDIX A

Itinerary **2nd September 2006 to 15th October 2006**

Saturday 2 nd September	Edinburgh to London Flying Scotsman
Sunday 3 rd September	Fly London to Seattle British Airways
Tuesday 5 th September	Professor Stuart Farber University of Washington School of Medicine Interview. Ward Round
Thursday 7 th September	Professor Denise Dudzinski Medical History & Ethics Department University of Washington Interview
Friday 8 th September	Professor Lisa Vig Geriatrics and Palliative Care Harborview Medical Center Interview
Saturday 9 th September	Research Papers ,Transcribing Tapes
Monday 11 th September	Professor Helene Starks Medical History & Ethics Department University of Washington Interview Professor David Gruenwald Elizabeth White(Senior Nurse) Palliative Care Team Veterans Administration Hospital Interview
Tuesday 12 th September	Clinical Meeting Medical Intensive Care Harborview Medical Center Darrell Owen Nurse practitioner Palliative Care Harborview Medical Center Ward Round & Interview
Wednesday 13 th September	Presented at Ethics Forum Harborview Research & Training Building

Physician assisted suicide v palliative care : a UK perspective

Friday 15 th September	Presented at Geriatrics Grand Round Conference Harborview Research & Training Building
Physician assisted suicide v palliative care : a UK perspective	
Monday 18 th September	Martin Hill, Radcliffe Publishing Seattle
Wednesday 20 th September	Professor Sarah Shannon Biobehavioural Nursing and Health Systems University of Washington Interview
Thursday 21 st September	Research and arranging meetings
Friday 22 nd September	Transcribing tapes
Sunday 24 th September	Amtrack Cascades Express Seattle to Portland
Tuesday 26 th September	Professor Linda Ganzini Veterans Medical Center Portland Multidisciplinary Team Meeting, Interview
Thursday 28 th September	Professor Susan Tolle Oregon Health Science University Meeting & Interviews
Friday 29 th September	Dr Richard Maunder Breakfast meeting with hospice doctors Interview at Providence Hospice Dinner with Palliative care staff
Sunday 1 st October	Professor Elizabeth Goy Meeting
Monday 2 nd October	Attended Conference Association of Health Faculty Survey Agencies Medicare & Hospice Ann Jackson Executive Director, Oregon Hospice Association
Tuesday 3 rd October	Travel to Salem Ann Jackson & Dr Sheila Sund, Dr Glen Patrizio

	Staff of Willamette Hospice Program
	Salem, Multidisciplinary team meeting
	Staff meeting to discuss PAS
	Home visit with hospice doctor
	Return to Portland
Wednesday 4 th October	George Eighmey
	Director, Compassion and Choice ,Oregon
	Afternoon meeting Oregon Hospice Association
Friday 6 th October	Palliative Care Conference, VA Medical Center
Presented	Challenges facing Palliative Care :a UK perspective
Saturday 7 th October	Travel Portland to Seattle Amtrak Cascades
Monday 9 th October	Transcribing Tapes
Wednesday 11 th October	Transcribing and research reading
Thursday 12 th October	Professor Randall Curtis
	University of Washington Medical School
	Interview
Friday 13 th October	Transcribing tapes
	Research reading
Saturday 14 th October	Depart Seattle British Airways
Sunday 15 th October	Arrive London Heathrow
	Fly Heathrow to Edinburgh

