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Exploring the concept of assisted dying in the UK

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Summary

This article discusses the concepts of euthanasia, assisted suicide and physician-assisted suicide, under the umbrella term of assisted dying, from a pro-assisted dying perspective. It outlines the key principles underpinning the debate around assisted dying and refutes the main arguments put forward by those opposing legalisation of assisted dying in the UK.

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ASSISTED DYING is an area of political and professional debate in the UK and across Europe. Nurses are expected to understand the key issues to engage in informed debate and support patients who may wish to discuss or explore this area in more detail. This article discusses some of the issues surrounding the concept of assisted dying. Assisted dying is a vast and complex subject, with many varying and often polarised views and opinions. It is important to emphasise that this article presents a predominantly pro-assisted dying perspective. The reader is encouraged to examine the broader literature to explore the topic in more depth. While there

are proponents and opponents of assisted dying, some have chosen to adopt a neutral stance in the debate (Royal College of Nursing (RCN) 2009a).

The article defines the terms that are often used in the assisted dying debate, outlines key principles underpinning assisted dying, clarifies the legal position in the UK and considers the role of the nurse in supporting patients in exploring this topic. It is important to note that although debates around assisted dying may raise awareness, they relate to only a small minority of deaths in those who are terminally ill.

Assisted dying

Assisted dying has been defined by Dignity in Dying (2010), the pro-assisted dying campaign group, as follows: 'Assisted dying (legalised and regulated in the US States of Oregon and Washington) only applies to terminally ill, mentally competent adults and requires the dying patient, after meeting strict legal safeguards, to self-administer life-ending medication.'

While the author acknowledges that this definition of assisted dying is limited because it refers only to terminal illness, it is nonetheless the description most often used in the UK. Other countries have their own definitions, eligibility criteria and approaches to assisted dying, and nurses, especially those who intend to practice in other countries, would be well advised to review these. It is also useful to consider arguments opposing assisted dying.

By using the term assisted dying there is an important distinction to be made. Dying is a natural and inevitable end to the life process. The term assisted dying implies the support, care and assistance offered to patients who have decided that they want to end their lives and require medical intervention to do so. Other terms used in the

debate are assisted suicide, physician-assisted suicide and euthanasia. Assisted suicide implies a conscious and deliberate effort to end life prematurely with medical or nursing assistance. The literal translation of euthanasia from Greek is good death (eu = well or good and thanatos = death). The definition is often inaccurately taken to imply that the consent of the individual may be absent. There is an important distinction to be made between the above concepts, as they all have differing underpinning ethical and moral stances. Generally, those in favour of helping terminally ill, mentally competent adults to end their lives at a time of their own choosing use the phrase assisted dying. This may be because it has less negative or value laden connotations than other more emotive terms. Those who oppose such actions tend to use terms such as assisted suicide or euthanasia. However, the terms assisted suicide, physician-assisted suicide and euthanasia are used in law and policy documents because they are clear in terms of intent, for example:

- ▶ Assisted suicide is the process by which an individual is provided, by another person or persons, with the means and the assistance (via drugs or equipment) to commit suicide. The key difference between assisted suicide and suicide is the word assisted. The person wants to die and has involved someone else in this endeavour (RCN 2009b).
- ▶ Physician-assisted suicide is where a doctor prescribes a lethal drug, which is administered by the patient or a third party, such as a nurse or relative (RCN 2009b).
- ▶ Euthanasia has been defined by the House of Lords Select Committee on Medical Ethics (1994) as ‘...a deliberate intervention undertaken with the express intention of ending a life, to relieve intractable suffering’. The word intervention connotes some act, rather than omission, by which life is terminated. Someone else is involved and the act of euthanasia may be carried out with or without the consent of the person who dies.

Although these terms are used interchangeably and each has specific meaning, assisted dying or assisted suicide are used in this article.

Background

Ending a person's life prematurely, or helping someone to end his or her life, is illegal in the UK. Attempts to change the law in the UK have so far

failed (Padain 2003). For example, Lord Joffe attempted to introduce legislation to legalise assisted suicide in the UK, but was unsuccessful (House of Lords 2005). In Scotland, Margot Macdonald brought similar legislation before the Scottish parliament, but that was also rejected (Howarth 2010). Following Debbie Purdy's campaign to clarify the law on assisted suicide, the Director of Public Prosecutions (DPP) in the UK issued guidelines on the circumstances in which a person who assists another person to end their life would be prosecuted (Purdy and Leedham 2009).

In Europe, assisted dying is practised in few countries, including Belgium, the Netherlands and Switzerland (Haigh and Neville 2009). The Belgian Act on Euthanasia 2002 decriminalised voluntary euthanasia. However, it did not define the acceptable method of euthanasia, so it can be assumed that this will be a matter of negotiation between the patient and physician (Humphrey 2005). Not having an accepted or agreed method of causing death in these situations may cause distress to the patient. In the Netherlands, euthanasia and physician-assisted suicide are regulated by the Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2002.

Switzerland has a legal infrastructure to support assisted dying, which is referred to as assisted suicide. Swiss citizens have been able to seek both physician-assisted suicide and non-physician-assisted suicide, in which medication is supplied by another healthcare professional, since 1941 in one of four assisted-dying centres. Dignitas is the only assisted-suicide group in Switzerland that offers assisted suicide to non-nationals. Since Dignitas was established in 1988, over 800 people have used its services to end their lives, with over 100 of those making the journey to Zurich from the UK (Johnson 2009).

There is no clear consensus in Europe on the benefits or otherwise of assisted dying (Cohen *et al* 2006a). This may be because different cultural factors have an effect on the overall attitudes of a population. For example, Germany is generally opposed to assisted suicide because of its history of Nazi mass murders, and strongly religious countries such as those in Eastern Europe are often opposed on religious grounds relating to the sanctity of life. However, the debate around assisted dying is growing, especially as Western countries become increasingly secular and more supportive of and open to the concept of citizen autonomy, which is the ability of citizens to challenge the dictates of government (Cohen *et al* 2006b).

Outside of Europe, the only other country to legalise assisted dying is the United States (US)

and that only applies to two states. Assisted dying has been legal in the state of Oregon for over 11 years, with Washington following Oregon's lead in 2009. The Death with Dignity Act 2008 in Oregon requires the state legislator to produce an annual report, based on voluntary reporting by the prescribing physician, identifying who has accessed right-to-die options under the act. This has resulted in a large body of evidence relating to people who choose an assisted death (Oregon Health Authority 2010). Efforts in the UK to develop assisted-dying legislation have been modelled on the Oregon regulations on physician-assisted suicide. The criteria in the Death with Dignity Act 2008 to protect vulnerable people are listed in Box 1. These include safeguards designed to protect vulnerable members of society such as those with dementia, depression and learning disabilities, as well as those who are dependent on others for their care needs.

Assisted dying in the UK

Debbie Purdy, who has multiple sclerosis, mounted a successful legal challenge to force the DPP in the UK to clarify explicitly whether her husband would face prosecution if she ever decided that she no longer wished to live and required him to accompany her to Switzerland (House of Lords 2009, Purdy and Leedham 2009). In February 2010, the DPP published *Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide* (DPP 2010), which outlined 16 factors in which prosecution would be in the public interest (Box 2). This was predominantly in response to Debbie Purdy's legal challenge as well as a number of high-profile cases, for example that of Daniel James (Brown 2008), in which the relatives and friends of patients were investigated under the Suicide Act 1961. The Suicide Act 1961 (Section 2 (1)) states that: 'A person who aids, abets, counsels or procures the suicide of another, or attempt by another to commit suicide shall be liable on conviction on indictment to imprisonment for a term not exceeding fourteen years'.

No person who has accompanied patients to Dignitas in Switzerland has ever been prosecuted. However, there is no guarantee that this pseudo-immunity (the fact that the reluctance to prosecute would be true in every subsequent case) from prosecution will continue.

The DPP (2010) guidelines also outlined six factors that would tend against prosecution, meaning that pursuing such individuals under the law would not be in the public interest (Box 3). However, the ruling and subsequent DPP (2010) guidelines did not change English law; only parliament has the ability to do that.

Furthermore, the ruling does not decriminalise the offence of encouraging or assisting suicide and the DPP (2010) policy does not provide assurance that a person will be immune from prosecution if he or she carries out an act that encourages or assists the suicide or attempted suicide of another person.

It is important to note that the DPP (2010) policy covers any act to assist suicide in England and Wales as well as cases where people leave the country to assist with a suicide. The law in Northern Ireland on assisted suicide is the same as that in England and Wales. The Public Prosecution Service in Northern Ireland published a similar policy (Public Prosecution Service for Northern Ireland 2010). The Scottish parliament has primary and secondary legislative powers to administer the Scottish legal system. The Scottish equivalent of the DPP has stated that similar guidance will not be issued in Scotland. There is no specific crime of assisted suicide in Scotland. However, people in Scotland who assist suicide may be liable for prosecution for the crime of culpable homicide under the Corporate Manslaughter and Corporate Homicide Act 2007.

Exploring the evidence base of the assisted dying debate

Evidence suggests that in the UK the general public are ready to consider a change in the law

BOX 1

Oregon Death with Dignity Act 2008 criteria

- ▶ The patient must make two oral requests to the attending physician, separated by at least 15 days.
- ▶ The patient must provide a written request to the attending physician, signed in the presence of two witnesses, at least one of whom is not related to the patient.
- ▶ The attending physician and a consulting physician must confirm the patient's diagnosis and prognosis.
- ▶ The attending physician and a consulting physician must determine whether the patient is capable of making and communicating healthcare decisions for him or herself.
- ▶ If either physician believes the patient's judgment is impaired by a psychiatric or psychological disorder (such as depression), the patient must be referred for a psychological examination.
- ▶ The attending physician must inform the patient of feasible alternatives to the Death with Dignity Act 2008, including comfort care, hospice care and pain control.
- ▶ The attending physician must request, but may not require, the patient to notify his or her next-of-kin of the request. A patient can rescind a request at any time and in any manner. The attending physician will also offer the patient an opportunity to rescind his or her request at the end of the 15-day waiting period following the initial request.

surrounding assisted dying (McAndrew 2010). It should be noted that the studies carried out relate to the public's and patients' hypothetical support for the legalisation of physician-assisted suicide. Assisted dying is perceived as a way of enabling individuals to maintain control over their own life and eventual death. However, terminally ill patients' support for legalising physician-assisted suicide and euthanasia is not

stable over time, and they become less supportive as their disease progresses. This may be because they begin to develop coping strategies to deal with their symptoms as well as their outcome (Pacheco *et al* 2003). Some healthcare professionals and members of the public vociferously oppose any changes in the law. The difficulty, as with any contentious issue, is to separate emotion and rhetoric from the evidence, and to examine the various arguments relating to assisted dying.

BOX 2

Public interest factors tending in favour of prosecution

- ▶ The victim was under 18 years of age.
- ▶ The victim did not have the capacity (as defined by the Mental Capacity Act 2005) to reach an informed decision to commit suicide.
- ▶ The victim had not reached a voluntary, clear, settled and informed decision to commit suicide.
- ▶ The victim had not clearly and unequivocally communicated his or her decision to commit suicide to the suspect.
- ▶ The victim did not seek the encouragement or assistance of the suspect personally or on his or her own initiative.
- ▶ The suspect was not wholly motivated by compassion; for example, the suspect was motivated by the prospect that he or she or a person closely connected to him or her stood to gain in some way from the death of the victim.
- ▶ The suspect pressured the victim to commit suicide.
- ▶ The suspect did not take reasonable steps to ensure that any other person had not pressured the victim to commit suicide.
- ▶ The suspect had a history of violence or abuse against the victim.
- ▶ The victim was physically able to undertake the act that constituted the assistance him or herself.
- ▶ The suspect was unknown to the victim and encouraged or assisted the victim to commit or attempt to commit suicide by providing specific information via, for example, a website or publication.
- ▶ The suspect gave encouragement or assistance to more than one victim who were not known to each other.
- ▶ The suspect was paid by the victim or those close to the victim for his or her encouragement or assistance.
- ▶ The suspect was acting in his or her capacity as a medical doctor, nurse, other healthcare professional, professional carer (whether for payment or not), or as a person in authority, such as a prison officer, and the victim was in his or her care.
- ▶ The suspect was aware that the victim intended to commit suicide in a public place where it was reasonable to think that members of the public may be present.
- ▶ The suspect was acting in his or her capacity as a person involved in the management or as an employee (whether for payment or not) of an organisation or group, a purpose of which is to provide a physical environment (whether for payment or not) in which to allow another to commit suicide.

(Director of Public Prosecutions 2010)

Argument 1: the slippery slope

The premise of the slippery slope argument is that if there is legislation legalising assisted dying for terminally ill people, there is the risk that vulnerable groups, such as older people or people with learning difficulties and mental illness, will be encouraged by their families to take this course of action against their will so that the family can be relieved from the burden of caring for them. Vulnerable individuals who perceive themselves as a burden may also feel that they should end their lives. The DPP (2010) guidelines illustrate that every effort has been made to protect vulnerable individuals.

Battin *et al* (2007) reviewed nine annual reports from Oregon (1997-2005) and four large national studies commissioned by the Dutch government. In addition, evidence from three other US surveys and several smaller Dutch studies were included. This gave an overall sample of 9000 deaths. Battin *et al* (2007) found

BOX 3

Public interest factors tending against prosecution

- ▶ The victim had reached a voluntary, clear, settled and informed decision to commit suicide.
- ▶ The suspect was wholly motivated by compassion.
- ▶ The actions of the suspect, although sufficient to come within the definition of the offence, were of only minor encouragement or assistance.
- ▶ The suspect had sought to dissuade the victim from taking the course of action that resulted in his or her suicide.
- ▶ The actions of the suspect may be characterised as reluctant encouragement or assistance in the face of a determined wish on the part of the victim to commit suicide.
- ▶ The suspect reported the victim's suicide to the police and fully assisted them in their enquiries into the circumstances of the suicide or the attempt and his or her part in providing encouragement or assistance.

(Director of Public Prosecutions 2010)

no evidence that older people were at heightened risk (the authors do not define heightened risk) of choosing assisted dying than other age groups. They also found that patients over 80 years formed 30% of the group for whom assisted dying was refused (Battin *et al* 2007). The 2009 Oregon Death with Dignity Act report noted that, as in previous years, 78% of people who took advantage of the assisted dying legislation were between 55 and 84 years of age (Oregon Health Authority 2010). Battin *et al* (2007) also reported that there was no evidence that the lives of women, minors or people with non-terminal physical or intellectual disabilities or chronic non-terminal illnesses (who they identified as vulnerable groups) were more frequently ended with a physician's assistance than those of other, less vulnerable groups of people. Therefore, it would appear that the anecdotal examples put forward by those who espouse the slippery slope argument do not stand up against this evidence. However, Battin *et al* (2007) did identify that people with acquired immune deficiency syndrome were at heightened risk; they were 30 times more likely to choose assisted dying than those who died of chronic respiratory disorders.

Argument 2: money will be diverted from palliative care services

This argument suggests that any money spent assisting patients to die will divert funds away from palliative care services. It is difficult to ascertain where the economic evidence for this argument may be found. For example, the Netherlands and the US rank higher than the UK in terms of basic end-of-life care, provision of healthcare environments such as hospices and national spending on health care. The UK has been consistently ranked first for palliative care both in Europe and the rest of the world (Economist Intelligence Unit 2010). This is often attributed to the fact that the UK has a long-established hospice care system that was in place at least a decade before other countries (Economist Intelligence Unit 2010). However, the Netherlands ranks fourth in Europe and seventh in the world for its palliative care provision (Centeno *et al* 2008, Economist Intelligence Unit 2010). There is no convincing evidence to suggest that provision of assisted dying adversely affects the quality of palliative care services.

Argument 3: the laws of God will be compromised

This is a powerful argument for those who have religious faith. The demand for a debate around the issue of assisted dying appears to be growing in Western countries as they become increasingly

secular (Cohen *et al* 2006b). Associated with this is the sanctity of life argument, which can be seen as a humanist concept, a moral statement and part of law. Many people with no religious affiliations are opposed to the legalisation of assisted dying and believe that it is wrong to bring about someone else's death, regardless of the circumstances, because of the sanctity of human life. It is therefore misleading to assume that this is solely a religious argument and that growing secularisation is increasing the demand for legalisation of assisted dying. For most people who support the notion of assisted dying, the focus is on individual autonomy and choice. However, many religious organisations, and some moralists, would argue that individual autonomy has an important limitation; that of preventing harm to others (Haigh and Neville 2009).

Portenoy *et al* (1997) found that healthcare professionals who professed a strong religious belief were less likely to support assisted dying and consider that it can not be justified under any circumstances. However, the question that must be asked is how far an individual's personal beliefs should be allowed to affect the care and choices of others. For example, it would not be appropriate for a nurse who is a committed vegetarian to refuse to order meat-based dishes for patients in his or her care. Therefore, it is questionable for the religious community to attempt to direct healthcare policy for those who do not share its beliefs.

Should assisted dying ever become legal in the UK, the existence of a conscience clause would allow nurses with reservations to ensure that they do not have to provide care or services in this instance. However, the UK National Secular Society (2010) pointed out that healthcare professionals have a duty to ensure that people who require services, for example abortion, are referred immediately and without question or judgement to those who are prepared to help.

Argument 4: trust will be eroded between patients and healthcare professionals

This argument suggests that patients will feel less able to trust healthcare professionals if physician-assisted suicide is legalised. However, as this article has tried to demonstrate, the existence of formal assisted dying legislation is more likely to protect patients from this scenario. Hall *et al* (2005) found that 58% of a sample of 1117 healthy US adults thought that assisted dying legislation would not weaken their trust in physicians. Most felt that a physician assisting in suicide or euthanasia would be as trustworthy as a non-participating physician in terms of caring for critically ill patients.

Argument 5: access to high quality palliative care will remove the need for assisted dying

Some people fear that focusing on assisted dying will divert resources away from palliative care services. They also argue that advances in modern palliative care and pain-relieving drugs mean that everyone can be assured a peaceful, pain-free death. Data from Oregon Health Authority (2010) showed that 54 people who died under the Death with Dignity Act 2008 were enrolled in hospice care, which suggests that, in Oregon at least, access to palliative care and treatments is not a deciding factor when considering assisted dying. A further flaw in the argument is the underlying assumption that it is unresolved pain or failure of symptom control that lead people to consider assisted

dying as an option. In total, 91% of people in Oregon who have made use of the Death with Dignity Act 2008 over the past 11 years have cited loss of autonomy as their primary end-of-life concern (Oregon Health Authority 2010).

Implications for nursing practice

In countries where physician-assisted suicide is legal, it is often the responsibility of doctors to prescribe and sometimes administer lethal drugs. However, it is nurses with whom patients often discuss the concept of assisted dying (van de Scheur and van der Arend 1998, Deliens *et al* 2000). The work of van Bruchem-van de Scheur *et al* (2008) in the Netherlands suggested that requests for assisted dying are most often discussed with nurses first and that, in 80% of cases, the nurse who was present during the administration of euthanasia had a role in the decision-making process. Therefore, familiarity

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with the debates around assisted dying is an important part of nursing care.

Despite the fact that assisted dying is not legal in the UK, patients may still want to discuss this issue with nurses. This may cause a dilemma for the nurse who may wish to explore with the patient the reasons behind any desire for hastened death. Hudson *et al* (2006) developed guidance in response to conversations of this nature. Research has shown that nurses feel inadequate when patients are distressed and do not know how to respond to them (Dickens *et al* 2008). Nurses who find themselves in this position should seek further professional development and training in this area of care so that they feel more confident and competent in communicating with these patients.

Conclusion

A large, prospective, cohort study, with a representative sample and historical controls

would be necessary to fully explore the arguments about assisted dying presented in this article.

The possibility of generalising the findings from research studies carried out in one country to another require greater exploration to establish what role, if any, cultural differences play in the interpretation of findings.

Current law makes it impossible for a nurse to participate in assisting a patient to die and the guidelines from the DPP in England do not change this. However, it is important for nurses to understand the rationale for any future changes in the law. The RCN (2009a) has chosen to adopt a neutral stance in this debate – neither supporting nor opposing any proposed change in the law.

However, the responsibility for ensuring that the nursing profession contributes to and understands the implications of any changes in end-of-life practice rests with each nurse, if the needs of individual patients are to be met **NS**

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