



Royal College of Nursing

When Someone Asks For Your Assistance To Die

RCN guidance on responding to a request to hasten death
2nd edition





Acknowledgements

Contributors to the second edition (2016)

Dr. Sally Anstey, Senior Lecturer, School of Healthcare Sciences, College of Biomedical and Life Sciences, Cardiff University

Laura Calvert, Legal Officer and Solicitor, Northern Region, Legal Services, RCN

Amanda Cheesley, Professional Lead for Long Term Conditions and End of Life Care, RCN Nursing Department

Shirley Fife, Macmillan Nurse Consultant Cancer and Palliative Care, Lothian

Helen Roberts, Lecturer in End of Life Care, Department of Health Sciences, University of York

Lisa Turnbull, Policy and Public Affairs Adviser, RCN Wales

Christine Ward, Nurse Consultant for Adult Palliative Care, South Tees Hospitals Foundation NHS Trust

Anderson Strathern (LLP), Scotland

Contributors to the first edition (2011)

Sally Anstey, Lecturer and Deputy Professional Head for Adult Nursing, Cardiff School of Nursing and Midwifery Studies, Wales

Maggie Bisset, Nurse Consultant in Palliative Care, Camden, Islington ELiPSe, UCLH and HCA Palliative Care Service, Head of Nursing, CNWL Camden Provider Services

Shirley Fife, Lead Cancer & Palliative Care Nurse, NHS Lothian

Kay Hardwick, Clinical Nurse Specialist, Palliative Care, Arthur Rank Hospice, Specialist Palliative Care Services, Cambridgeshire Community Services NHS Trust

Sue Pender, Modern Matron, City Health Care Partnership CIC

Helen Roberts, Lecturer in End of Life Care, Department of Health Sciences, University of York

Christine Ward, Nurse Consultant for Adult Palliative Care, South Tees Hospitals Foundation NHS Trust

Charles Foster, Barrister, The Ethox Centre, University of Oxford, Green Templeton College, and Outer Temple Chambers, London

Anderson Strathern (LLP), Scotland

The RCN Ethics Committee

RCN Legal Disclaimer

This publication contains information, advice and guidance to help members of the RCN. It is intended for use within the UK but readers are advised that practices may vary in each country and outside the UK.

The information in this publication has been compiled from professional sources, but its accuracy is not guaranteed. Whilst every effort has been made to ensure the RCN provides accurate and expert information and guidance, it is impossible to predict all the circumstances in which it may be used. Accordingly, to the extent permitted by law, the RCN shall not be liable to any person or entity with respect to any loss or damage caused or alleged to be caused directly or indirectly by what is contained in or left out of this information and guidance.

Published by the Royal College of Nursing, 20 Cavendish Square, London, W1G 0RN

© 2016 Royal College of Nursing. All rights reserved. Other than as permitted by law no part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means electronic, mechanical, photocopying, recording or otherwise, without prior permission of the Publishers or a licence permitting restricted copying issued by the Copyright Licensing Agency, Saffron House, 6-10 Kirby Street, London EC1N 8TS.

This publication may not be lent, resold, hired out or otherwise disposed of by ways of trade in any form of binding or cover other than that in which it is published, without the prior consent of the Publishers.

Contents

Preface	4
Introduction	5
The law on assisted suicide	6
The law on advance decisions	7
Professional accountability	9
End of life care	10
When and why people express a desire to die	11
Responding to a request to hasten death	13
Direct request from a patient	13
Direct request from a patient's family or carer	15
Frequently asked questions	17
Glossary of terms	20
References and further reading	21
Resources to improve end of life care practice	23

Preface

The topic of assisted suicide generates debate on a variety of levels – ethical, moral, religious, spiritual, political, cultural, psychological, professional and legal. By definition it is an issue that affects the nursing, and wider health and social care, workforce, both as individuals and as health professionals.

Intense media coverage of recent UK court cases and high profile testimonies has helped to project the current debate surrounding the legalisation of assisted suicide and voluntary euthanasia to the forefront of the public's consciousness. It generates emotions in all of us as it reminds us of our own mortality and humanity.

Since the first edition of this guidance was published, public conversations about dying, death and bereavement have become more prevalent. The Dying Matters' annual Awareness Week (England), the Festival of Death (Wales) and Good Life, Good Death, Good Grief/To Absent Friends Festival (Scotland), for example, all aim to raise public recognition of the need to think ahead and plan for death and dying, providing opportunities for people to come together to engage in 'everyday' conversations with others in a variety of public settings.

Similarly, ensuring – through sensitive enquiry – that people's preferences are heard, recorded, shared and acted upon as they live with their long term condition(s) and approach the end of their lives means that the importance of planning ahead has gained greater recognition as an important aspect of the health care agenda. Recent reports have highlighted the need for health professionals to adopt a patient and carer-centred approach and the importance of creating a supportive environment in which people are able to discuss planning for the future, death and the process of dying.

Most people who are approaching the end of their lives in the UK do not ask a health professional to hasten their death, but a minority of individuals do express a readiness or desire to die. Most patients expressing such sentiments do not go further by asking a nurse to hasten their death. However, when this does happen – or when someone close to the patient voices a request to hasten death – it can be difficult to know how to respond.

Nurses and support care workers are often the members of staff that patients, and those who matter to them, feel comfortable enough to approach and express a desire to actively hasten death. However, such requests can provoke concern for nurses and support care workers as they determine how best to respond professionally and compassionately to such a request and continue to support patients in their ongoing care. This is particularly difficult when patients are not close to death and are persistent in their request.

As a result, nurses and other health care professionals are turning to the Royal College of Nursing (RCN), seeking advice about the best and most appropriate response to such requests and greater clarity about their role and responsibilities in such scenarios.

This guidance has been developed to support the nursing workforce and other health and social care professionals in practice who may be asked by patients, and/or those who are important to them, to become involved in assisting suicide or actively hastening death.

This updated edition contains new and additional resources that may help guide you to undertake and navigate these difficult conversations.

Introduction

Nurses and support care workers are the staff that patients and those important to them most frequently encounter on a daily or regular basis. As a result, they may feel comfortable approaching them with ‘desire to die’ conversations.

These conversations may go on to take the form of an explicit declaration or a direct enquiry about seeking assistance to die. More often patients and those important to them may ‘test the water’, using phrases, euphemisms or indirect references that signal a desire to openly discuss their wish for a hastened death. It may be a cry for help, an expression of their distress or a well thought out desire to die.

Nurses, and other health and social care practitioners may feel uncomfortable or unsure about how to respond to such situations, and may feel inadequately prepared to engage in these conversations in case they say ‘the wrong thing’ in response. They may also feel concerned about their legal position and be anxious about potential professional sanctions. As a consequence, they may close down the communication quickly, leaving the patient – or those important to them – feeling isolated and with no outlet for discussing their needs and concerns.

The Parliamentary and Health Service Ombudsman’s 2015 (England) report notes; “Poor communication with the person who is dying, and those close to them, means there are uncertainties, unrealistic expectations, indecision about preferences, and missed opportunities for better care...”.

When hearing a desire to die request or statement, it is common to feel fear and panic, professional uncertainty, or to feel intimidated, or even to over identify with the person’s situation. Remembering meaningful experiences from our own personal lives is also likely, and will impact on our emotional response.

Given this context it is not surprising that even experienced practitioners are hesitant to know how to proceed.

The purpose of this publication is to support you in your practice when you are faced by patients - and those important to them - who feel their life, for whatever reason, is, or will be, unendurable and unbearable, and who ask for your assistance to die.

Whether you’re a pre-registration student, a registered nurse, health visitor, midwife, or a support or care worker, conversations about the end of life may arise at some point in your practice. Regardless of whether you work in people’s own homes, a care home, a hospice, a hospital, or a prison, at some time in your career you are likely to encounter a situation where someone wants to talk with you about death and dying, or ending their own, or another’s life. The increased focus on future and advance care planning at the end of life, and wider public promotion of the need to think ahead about such issues, means you may find these types of conversations occurring with greater frequency.

The RCN is dedicated to the nursing workforce to become more knowledgeable and skilled in supporting patients who require palliative care or are facing the end of their life. Several resources for improving clinical practice and which may be helpful in having these conversations have been included at the end of this publication.

Conducting difficult conversations is central to the provision of high quality palliative and end of life care. The RCN recognises that there is a clear distinction between the therapeutic end of life decisions taken as part of palliative and end of life care, and actively taking actions to end life which is a feature of assisted suicide or euthanasia (both of which are unlawful).

Assisted suicide is illegal in all parts of the UK.

The law on assisted suicide

There have been several recent calls for changes in the law to allow physician-assisted suicide, all of which have been debated and rejected by UK parliaments. The current legal position on assisted suicide across the four UK countries is outlined in more detail below.

England and Wales

Assisting or encouraging another person to commit suicide is an offence under section 2(1) of the Suicide Act 1961 and as amended by section 59 of the Coroners and Justice Act 2009. Violation of section 2 of the Suicide Act 1961, which makes it unlawful to ‘do an act capable of encouraging or assisting the suicide or attempted suicide of another’, intending that act to encourage or assist suicide or an attempt at suicide, carries a maximum penalty of 14 years’ imprisonment.

Furthermore, if an individual (A) arranges for someone else (B) to do an act that is capable of encouraging or assisting the suicide or assisted suicide of another person (C), and B carries out that act, then A is treated by the law as having committed an offence.

Following an extensive public consultation in November 2009, guidance was subsequently issued by the Director of Public Prosecutions (DPP – England and Wales) for prosecutors, setting out the factors to be considered for and against a prosecution. A prosecution is more likely, for example, to be required if:

- 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 suspect was acting in his or her capacity as a medical doctor, nurse or other health care professional, a 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.

First tabled in the House of Lords in June 2014, Lord Falconer’s Assisted Dying Bill was defeated in September 2015, when MPs in the House of Commons voted against changing the law to allow doctors to help terminally ill people end their lives.

Northern Ireland

Like its counterpart in England and Wales, the Criminal Justice (Northern Ireland) Act 1966 decriminalised suicide in Northern Ireland but specifically retained the offence of complicity in the suicide of another. The act has now been amended by the Coroners and Justice Act 2009 to provide for an identical offence as in England and Wales, and carries the same maximum sentence of imprisonment.

Scotland

Although there is no specific statute relating to suicide, it is currently the case that assisting or attempting to assist a suicide is likely to constitute a criminal offence.

To date, two bills – the End of Life Assistance (Scotland) 2010 and Assisted Suicide (Scotland) 2013 – have been introduced in the Scottish Parliament in an attempt to set out new legislation on assisted suicide for Scotland; the bills were defeated in December 2010 and May 2015 respectively.

In February 2016, in a case called *Gordon Ross v Lord Advocate* [2016] CSIH 12, the court confirmed that it is “in accordance with the law” to criminalise those who assist others in their suicide. Both the Lord Advocate and the Crown Office believe that there is no need for Scotland to develop specific guidance for assisted suicide cases as the general Prosecution Code (which sets out the public interest factors that must be taken into account when determining whether or not to prosecute) already exists.

The law on advance decisions

UK law draws a crucial distinction between, on the one hand, actively causing someone to die (murder) or encouraging or assisting them to bring about their own death (assisting suicide) - both of which are unlawful - and on the other, the withdrawal or withholding of life-sustaining treatment (which may be lawful).

An advance decision to refuse treatment is a statement of future wishes. If it is 'valid and applicable' (in the words of the England/Wales Mental Capacity Act 2005) it has the same effect as if it were made by a patient who has the capacity to make it at the time it becomes relevant. For instance, a person with capacity may say through an advance decision that they wish to refuse treatment that might prolong their life if they become physically incapacitated. The advance decision therefore ensures their wishes are taken into account at the time they become physically incapacitated and lack the mental capacity to be able to consent or not to any treatment.

A patient cannot use an advance decision to insist on any specific treatment or to request anything unlawful, such as help committing suicide.

The question of the relevance and applicability of advance decisions is often medically and legally complex. Where an advance decision exists, a record of this should be saved in the patient's health record and made available to clinicians both in and out of hours; the use of electronic systems for the key information, for example, should be explored. It will often be appropriate to discuss the relevance of an advance decision in a multi-disciplinary meeting and if there are any concerns, you should escalate for further investigation.

Whilst advance decisions are used across the UK, there are distinct differences in the legal framework which affects how they are applied. These differences are outlined below.

England and Wales

Advance decisions in England and Wales are covered by the Mental Capacity Act 2005, which became law in April 2007. An advance decision concerned with the refusal of life-sustaining treatment must be made in writing, and must be signed and witnessed.

Sometimes a patient will have created a lasting power of attorney (LPA) which gives a third party (the attorney) a right to make some decisions on their behalf. The requirements for the creation of an LPA are very formal and strict. If someone claims an LPA exists, you should check that the document is valid and has been registered with the Office of the Public Guardian (OPG), request to view a copy of the document, take a copy and record this in the patient's notes. An attorney can only refuse life-sustaining treatment on behalf of someone if the LPA specifically gives the attorney that power.

If an advance decision is not 'valid and applicable' it will not be binding. This might be, for instance, if the prognosis for a condition envisaged in an advance decision is very much better than it was at the time the advance decision was made – so that the person who made the advance decision may have made a different decision.

Advance decisions can cover clinically assisted nutrition and/or hydration, or a DNACPR (do not attempt cardiopulmonary resuscitation) decision. Policy guidelines on DNACPR for England and Wales can be obtained from the Resuscitation Council (UK) www.resus.org.uk

Northern Ireland

In Northern Ireland, advance decisions are governed by common law rather than legislation. However, providing the decision was made by an adult with capacity and clearly sets out the person's intentions, it is likely that a court would consider it legally binding.

The '*Bamford Review of Mental Health and Learning Disability*' was set up in late 2002 to examine how services for people with mental illness or learning disabilities could be improved. Following the close of the review in 2006, a policy consultation document was produced (Legislative framework for mental capacity and mental health legislation in Northern Ireland) which advocated that a new Mental Capacity Bill be enacted and in May 2016, the new Mental Capacity Act (Northern Ireland) 2016 came into force.

Scotland

In Scotland, individuals can appoint one or more persons with power of attorney which either continue or begin in the event of incapacity. Different attorneys can be appointed for each type of power of attorney; a continuing power of attorney can help with financial matters; a welfare power of attorney gives power over decisions that need to be taken about the granter's welfare and health care which only begins if the granter becomes incapable. A power of attorney must be registered with the Office of the Public Guardian (Scotland) before it can be used. If someone claims a welfare attorney exists, you should check the document has been registered with the Office of the Public Guardian, request to view a copy of the document, take a copy and record this in the patient's notes, including their key information summary.

In Scotland the Adults with Incapacity (Scotland) Act 2000 obliges clinicians to take into account the 'present and past wishes and feelings' of any patient deemed 'incapable', as far as it is reasonable and possible to know these. It is good practice to take into account the views of those important to the patient; this may include the nearest relative/primary carer. You must take into account the views of any appointed guardian, welfare attorney or person(s) nominated to take decisions by the patient, including under a power of attorney granted when they were capable, or any person the Sheriff has directed to be consulted, where it is reasonable and practical to do so. It is also good practice to consult members of the health care team when making decisions.

The definition of medical treatment in Scottish legislation clearly states that any intervention made when someone is 'incapable' must be designed to 'promote physical or mental health'. As in England and Wales, a person could set out their wishes in advance in writing not to receive certain treatments – such as CPR. However, a clinician could not engage in any intervention that would actively assist a suicide, even if the person has asked for this assistance while they were still capable.

You can access the recent 2016 update to the NHS Scotland policy guidance *Do not attempt cardiopulmonary resuscitation (DNACPR) – integrated adult* online at:

www.gov.scot/Resource/0050/00504976.pdf

Professional accountability

The Nursing and Midwifery Council (NMC) is the UK regulator for nurses, midwives and specialist community public health nurses. Nurses are required to follow the NMC's *Code: standards of conduct, performance and ethics for nurses and midwives* (2015), which directs nurses to:

- keep to the laws of the country in which you are practising
- make sure that people's physical, social and psychological needs are assessed and responded to – in other words, to prioritise people
- to practise effectively and act without delay if you believe there is a risk to patient safety
- share information if you believe someone may be at risk of harm
- acknowledge and act on all concerns raised to you, investigating, escalating or dealing with those concerns where it is appropriate for you to do so
- not obstruct, intimidate, victimise or in any way hinder a colleague, member of staff, person you care for or member of the public who wants to raise a concern
- promote professionalism and trust
- be a model of integrity and leadership for others to aspire to.

Following a review published by The Commission on Assisted Dying, set up by the campaign group Dignity in Dying and chaired by Lord Falconer, which recommended that some adult patients could safely be offered the choice of assisted dying, in January 2012 the NMC issued a statement in which it announced:

“Nurses and midwives are personally accountable for their actions and must act lawfully at all times...Assisting the suicide of a patient is against the law.”

Published in March 2013, the *Code of Conduct for Healthcare Support Workers and Adult Social Care Workers in England* provides a clear set of standards that include ensuring you “always behave and present yourself in a way that does not call into question your suitability to work in a health and social care environment” and “always make sure that your actions or omissions do not harm an individual's health or wellbeing.”

In Wales the *Code of Conduct for Healthcare Workers in Wales* (2011) clearly states that health care support workers (HCSWs) are expected to “behave in a professional manner which would not call into question your suitability to work in a health care environment.” It also states that as an HCSW you must maintain “clear and appropriate professional boundaries in relationships with service users.” In addition, the *Code of Professional Practice for Social Care* (2015) states that social care workers, who are defined as ‘any paid worker contributing to the delivery of social care and support’, are expected to ‘act with integrity and uphold public trust and confidence in the social care profession’. From April 2017 the Care Council for Wales, which regulates care home managers and provides both the code of practice and educational and employment support to those working in care homes, will become known as Social Care Wales and will take on additional responsibilities, including registering home care and adult care home workers.

In Scotland, the *Code of Conduct for Healthcare Support Workers* (2009) identifies the requirement to “always do what is right to protect the patient or member of the public for whom you provide a service” and states that as a support worker “you are expected to work to a certain standard”.

In Northern Ireland, the NISCC recently launched its new *Standards of Conduct and Practice for Social Care Workers and Social Workers* in November 2015.

RCN resources for registered nurses and health care support workers on issues surrounding accountability, delegation and dignity can be found towards the end of this document.

End of life care

The RCN recognises there is a clear distinction between *end of life* decisions taken as part of palliative care, thinking ahead (advance care planning), and the concept of *acting to end life*, which is a feature of assisted suicide. The core ethical principle focuses on the intent of the action, for example, to achieve optimal pain control or hasten death.

Many people facing death retain meaning and purpose in their life, even when death is very close. People can be remarkably resilient to the changes illness brings. The aim of good palliative and end of life care is to conserve and enhance dignity and to diminish sources of suffering, no matter if the cause is physical, emotional, social, spiritual or practical.

Social and cultural inhibitions surrounding any discussion about death may make it challenging for some patients and health care professionals to engage in frank and open discussions about end of life care and support. Several resources for improving clinical practice, and which may be helpful in prompting these discussions, are included at the end of this publication.

For some people, acknowledging they are dying is an essential first step towards ensuring they are able to plan to live well until they die. For others, however, talking about dying and the end of life is simply too distressing. The General Medical Council's 2010 guidance *Treatment and care towards the end of life: good practice in decision making* makes it clear that early, sensitive discussion and planning about how best to manage a patient's care is essential and that you must support them to communicate their wishes and that it is your responsibility to have these conversations.

Such taboos may also make it difficult for health professionals to uncover the concerns and fears about death and dying confronting patients and their families. But it is important to dispel some of the commonly held myths and misconceptions patients may hold about death and the process of dying such as: that it is always painful; that how they die is completely out of their hands; that pain relieving drugs only work in highly toxic doses; to be functionally dependant is undignified.

A recent report by the Care Quality Commission (2016) highlighted how people from certain groups in society sometimes encounter barriers which may prevent them from experiencing good, personalised end of life care because health care providers do not always understand or fully consider their needs. You have a duty, under the

Equality Act 2010, to take an equality-led approach to individuals, regardless of their diagnosis, age, ethnic background, sexual orientation, gender identity, disability or social circumstances.

The RCN believes that when patients are offered skilled palliative and end of life care, requests for assisted suicide may become less frequent. Patients can find discussing end of life concerns very useful, even when many years away from dying, as conversations such as these can lessen fears that can strengthen and evolve into a belief that assisted suicide is the only way dignity and control can be assured at the end of life.

In Scotland, this is something which is recognised in the Scottish Government's *Strategic Framework for Action on Palliative and End of Life Care 2016-2021*, which encourages open conversations about death and dying and sets out the Scottish Government's commitment to ensuring that everyone who needs it is able to access palliative care. This follows on from the Scottish palliative care guidelines introduced in 2014.

Nurses caring for people with progressive ongoing illness and/or long term conditions should use open questions to elicit early important concerns such as:

“Have you any thoughts or questions about your future needs or care?”

“I wonder if you would like to spend some time with me thinking about what you might experience as you continue to live with your illness.”

“Can you tell me about the sort of things that concern you most about the future?”

“What do you feel is most important to you?”

It is often through such sensitive enquiry that patients, and those who are important to them, can start to have meaningful conversations amongst themselves and with health and social care professionals. These conversations may be the first steps towards developing an anticipatory and/or advance care plan (ACP). A copy of the most up-to-date ACP should be made available to everyone involved in caring for the patient in any care setting. Out-of-hours care providers need access to all relevant information about the patient, including their advance plan, in order to support effective decision making in the event of being called upon to intervene in the out-of-hours period. Useful resources to support you with advance care planning are included at the end of this guidance.

When and why people express a wish to die

When patients talk directly or indirectly about a desire to hasten death they may be trying to tell you that, from their perspective, life is no longer worth living, that the future looks bleak, and that at this point in time they are unable to see “any light at the end of the tunnel.” Other patients may anticipate that this will become their outlook if specific events relating to their illness unfold.

Patients who make such statements or who seek information or help in relation to assisted dying are cared for in a variety of clinical settings. They may include:

- people with life-threatening illnesses approaching the end of life
- those with progressive irreversible conditions who predict a future situation in which they perceive their life will not be tolerable
- individuals who are physically disabled following a trauma or injury, and perceive their quality of life as being extremely poor and who see no potential for improvement
- those with mental health and learning disability issues for whom continuing to live feels like a major challenge
- individuals coping with complex, debilitating, or multiple long-term conditions.

Regardless of the context of care or area of practice you are working in, the expression of a desire or wish to die by a patient indicates that there may be underlying physical, practical, emotional and spiritual issues that need to be acknowledged and explored.

Faced with a serious debilitating illness many patients understandably may experience or anticipate psychological distress and feelings of hopelessness, some may lose all meaning and purpose in life and may have concerns relating to a number of factors, including:

- loss of autonomy and function
- decreasing physical and mental capacity
- loss of control
- loss of dignity
- exhaustion
- becoming a burden to relatives or friends
- dealing with distressing physical symptoms
- fear of the future
- social isolation
- the consequences of treatment/non-treatment.

Discussing fears, expectations and concerns with patients and their families can feel daunting because it involves exploring people’s intimate and private beliefs. For this reason some patients may resist such conversations and this should be respected, but you should aim to ‘leave the door open’ and give people an opportunity to revisit; this is a dynamic process, and concerns and wishes can change over time.

Even for experienced palliative care professionals, engaging in such discussions can throw up professional dilemmas and personal challenges. However, it is the role and responsibility of all health and social care professionals to have these conversations. If you are not confident about your ability to engage in such conversations, you will need to refer the patient on to someone who can – you must not deny an individual an opportunity to voice their concerns, fears or expectations. You should also discuss any training requirements and needs with your line manager.

While you may not feel confident or competent to pursue an in-depth conversation, at the very least you should acknowledge what the patient, or those important to them, has said. This demonstrates you recognise these are important feelings that need to be explored, and indicates your willingness to talk about the issues they are facing.

Showing empathy and being open to hearing concerns is the first important step towards making it possible for patients to have a meaningful conversation, during which you can begin to understand and explore the specific issues that need to be addressed.

It is important to remember that when you encounter these conversations, your personal beliefs relating to suicide and assisted suicide must be put to one side. You should not abandon, judge or chastise a patient for voicing their feelings, and your body language, tone, and manner should be neutral and sensitive to the moment. You should be aware of your own emotional response and be mindful about your personal resources in relation to being able to continue this dialogue without becoming noticeably overwhelmed.

When responding to a desire to die statement, you should take time to explore the background to the request. Understanding the meaning behind any such a request is central to formulating a professional response and an appropriate plan of action.

You may need to have a number of conversations with a patient and, with their consent, those important to them, to better understand their thoughts and motives. Some patients may not be able to talk about this more than once as it is so moving for them and/or perhaps they are frail and very near to death. For some it may be enough comfort just to share these thoughts and to know that their natural death is closer than they expected.

During these discussions it is helpful to:

- use a conversational approach to explore thoughts, feelings and expectations
- ask questions that probe emotional or practical concerns
- show empathy by staying with and acknowledging their situation; avoid sympathy
- check their understanding about their condition
- explore whether they have appropriate social support
- attempt to identify any helpful interventions to improve quality of life, including practical and emotional support and symptom management
- assess mental capacity/incapacity
- screen for psychological distress or issues particularly related to psychological wellbeing, remembering that sadness is an appropriate response to their situation
- explore why the person is asking for help to die
- seek agreement to have ongoing discussions to check understanding and whether concerns and expectations have changed
- explore if these discussions have happened with other health care professionals and/or those who are important to them
- support the patient to have a voice in the planning of their future care
- explain that information regarding their wishes may need to be shared with the multidisciplinary and out-of-hours teams, but that this information will be treated with respect and will help ensure they receive the best possible care
- make it clear you cannot do anything that would shorten life, but neither would you do anything which is against their wishes.

You must ensure you document all conversations and share any insights with colleagues and other members of the multidisciplinary team. You should share the patient's reasoning relating to a desire to die statement as this may help inform the multidisciplinary team with follow-ups or referrals. You will also need to advise other members of the care team of your discussions, sharing the patient's reasoning relating to a desire to die statement.

Several resources for improving clinical practice, and which may be helpful in prompting these discussions, have been included at the end of this publication.

If a patient goes on to request help with assisted suicide, the next section of this publication may help you formulate your response.

Responding to a request to hasten death

As a nurse or health and social care professional, you have a duty to help people without prejudice, and in a way that makes them feel listened to, that their situation is appreciated, and that you are trying to understand.

Your responsibility is to work within the law to support the patient, and those who are important to them, to explore and express their thoughts about the situation. At all times you are required to act ethically and legally, and in a manner that as far as possible empowers and supports people to live well until they die.

In the scenarios that follow, you'll find practical suggestions designed to guide you through how to respond appropriately to a request to hasten death. These recommendations are grouped under three headings:

Stop and think

Here you will find the legal or regulatory requirements which should frame your actions.

Approach

The suggested actions you'll find here are based on existing best practice or available evidence. You can try to employ these approaches in your practice, or perhaps discuss these actions with the multidisciplinary team. Resources and materials in support of these steps can be found at the end of this guidance.

Reflect and discuss

An opportunity to review some of the issues and dilemmas you may encounter. It may be useful to discuss these in more detail with your colleagues, the multidisciplinary team, or your clinical supervisor. Reflecting and discussing may help you think through your response, and the support you can offer a patient, and those who are important to them.

Direct request from a patient

You may be approached by a patient or someone in your care who directly asks for your assistance in hastening death. They may say things like 'I wish you could just give me something to die' or simply ask you if you are aware of any organisation that could help them to die. This section will help guide you on how to respond in such circumstances.

Stop and think

It is against the law to perform an act capable of encouraging or assisting the suicide or the attempted suicide of another person.

If a patient persists in asking for information about organisations that may be sympathetic to assisted suicide, or directly asks for assistance to die, it is important to make it clear that you cannot do anything that would shorten their life, or provide information about or assist in contacting such organisations.

A request for assisted suicide should prompt a discussion to draw out the reasoning behind the request through a non-judgemental assessment of needs. This may help uncover previously unrecognised or unmet needs, enabling the ongoing care planning to evolve as the patient's needs become clearer or change.

If the patient's expressed wishes are enduring, they are aware of the options available to them, have considered the consequences, and have mental capacity, then in England and Wales they may wish to prepare an 'advance decision to refuse treatment'.

However, as stated previously in this document, the law on advanced decisions is clear; a patient cannot use an advance decision to request anything that is unlawful, such as help committing suicide.

In Scotland, the law provides that a patient's wishes regarding treatment for their mental disorder can be recorded in writing in an advance statement under the *Mental Health (Care and Treatment) (Scotland) Act 2003* (where that Act is applicable). In other cases, these can be stated verbally by the patient for the clinician to record, or put in writing by the patient. Such recorded wishes will be taken into account when making treatment decisions. In Scotland, it is also possible for someone aged over 16 to make an advance directive (known as a living will) – although this is not legally binding, it can be taken into account when making treatment decisions. The Mental Welfare Commission for Scotland has produced a

useful guidance document on advance statements (Mental Welfare Commission for Scotland, 2014).

In 2010 the General Medical Council issued guidelines for doctors – *Treatment and care towards the end of life: good practice in decision making* – and you may want to refer to these for guidance. The GMC website also provides a number of learning resources, including an interactive mental capacity decision support tool, which can be found at http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp.

Consideration should be given to the cultural and religious implications of their request.

Approach

- **Listen very carefully to what is being said (and what is not said)**, and check you have understood the patient's concern accurately. Some patients from time to time express that they wish to die or 'are ready' to die. However, this is different from someone asking for help to hasten their death through assisted suicide.
- **Be gentle but direct in reflecting back** what you heard and clarify your understanding, as patients sometimes talk about issues concerning death using metaphors that can be confusing.
- **If the patient is asking specifically for your help with assisted suicide it is essential that you acknowledge the request and resist the inclination to 'ignore' or abandon the conversation.** Remarks around the serious nature of this request can help to ensure the person understands you recognise the importance of the situation and wish to understand more about what they are experiencing to come to such a position.
- **Acknowledge and communicate your own concerns about the patient's wellbeing and safety.** You will also need to let the person know that it is not possible to keep requests such as this private and in confidence. You may want to explain you intend to discuss this with their medical practitioner or other members of the team and that the aim of this disclosure is to seek support for the patient, and not to report wrongdoing.
- **Your tone of voice is important as it can denote seriousness, compassion and caring.** Your aim is to understand how the patient perceives dignity and to create nursing interventions which attempt to meet their needs.
- **As part of this process you can offer to arrange support or expert help for the patient so they may explore further their fears or concerns or expectations, and their understanding of their diagnosis, disease, or impact of multiple conditions.** Offering to set up a meeting with the medical practitioner in charge of their care to explore their diagnosis or condition more thoroughly may be a useful first step.
- **If you feel comfortable enough to pursue a more in depth conversation, you should attempt to explore the patient's current situation and how long they have been thinking about making this request.** Understanding who they have confided in is also important, as some people may not have been able to talk to anyone else regarding their wish for assisted suicide.
- **If you feel you lack the skills or expertise** to discuss and uncover the meaning that has led to such a request or statement, you should explain to the patient that you would like a more experienced colleague to speak to them. You should then seek support from another member of the team or the patient's medical practitioner. Other sources of support may include your mentor, clinical supervisor, colleagues, specialist palliative care team, mental health practitioner, and/or chaplaincy service.
- **Acknowledge the patient's feelings and concerns regarding their illness, and gently probe for more details about their perceptions of their illness, prognosis, death and dying.** Patients can have ideas about future physical and psychological distress, cognitive and functional capacity, dependence or vulnerability that may be beneficial to explore further in order to respond appropriately.
- **During your exploratory conversations, you should attempt to inform the patient about the legal position in the UK and identify any helpful interventions that are available within the law.** These might include further practical and emotional support, and symptom management options. As part of this discussion it is helpful to emphasise that they do not have to make hasty decisions, and you recommend that they take further time to talk with staff to fully explore their future options – which may include the choice not to have any further medical treatment, practical and emotional support, or symptom management options.

- **You have a professional duty to continue to provide nursing care and support in a professional and non-judgemental way.** It is important that you continue to maintain a professional relationship with the patient and keep the communication paths open so that they can continue to express their personal feelings, ideas, needs, and concerns and expectations. Many people who request assisted suicide change their mind or may never make specific plans.
- **You should ensure you document all conversations, and share any insights with colleagues and other members of the multidisciplinary team.**

Information on resources to help you with your palliative and end of life care practice is included in the closing sections of this publication.

Reflect and discuss

Before and after being involved in a conversation relating to a request to hasten death, you may wish to discuss the situation with your colleagues. Questions like ‘Why do people make a direct request?’ and ‘What is the meaning behind the request?’ are useful places to start.

Irrespective of your individual values and beliefs, your role is to offer ongoing support and care and to act within the parameters of the law and your professional responsibilities, and you need to ensure that the patient is aware of this. The challenge is how to manage your responses and feelings in the light of the patient’s statement or ultimate decisions, ensuring this does not impact upon the quality of care you deliver or your relationship with the patient.

How do you determine, in your professional judgement, if it is appropriate to pursue a conversation of this nature at this point in time? Will having the conversation help or hinder the patient? Do you believe the patient is experiencing fluctuating capacity? Do you think that tomorrow they may have a completely different perspective?

During such conversations you will be explicitly talking about the circumstances of an individual’s death, and this may stir strong emotions – both during the discussion and after – that need to be considered. Your manager may be able to help you identify support networks or clinical supervision that can help you deal with addressing these feelings.

If a patient does not wish to pursue the conversation at any point, you need to respect this decision, but you may wish to revisit the conversation at some point in the future. It may be helpful to reflect that for someone to have these discussions with you it may be a sign of your approachability and professional skills that make them feel comfortable in sharing their vulnerability with you.

Direct request from a patient’s family or carer

You may be approached by the individuals close to a patient you are caring for, who directly ask for your assistance in hastening their death. They may say things like “he would not want this – can you do something to help him?” This section will help guide you on how to respond in such circumstances.

Stop and think

It is against the law to do an act capable of encouraging or assisting the suicide or attempted suicide of another person. You must make this clear to the ‘significant others’ who have approached you and clarify you cannot do anything that would shorten the life of their relative, nor can you provide information about, or assistance in, contacting organisations that may support assisted suicide.

A family request to hasten the death of a relative/friend/significant other should prompt a discussion to draw out the reasoning behind the request through a non-judgemental assessment of needs. This may help uncover previously unrecognised or unmet needs of both the family/people of importance and the individual, enabling the ongoing care planning to evolve as the patient’s needs become clearer or change. It may also signal that the family/carer/friend or significant other would like to be more informed or involved in the advanced care planning process.

This conversation may also unearth concerns or confusion around the patient’s capacity to make decisions independently. In this situation you will need to seek guidance from senior staff with the authority and experience to organise any such assessment of capacity and make proper plans in response to the findings of the assessment.

If you are in any doubt about the safety and wellbeing of the patient and consider them to be an adult at risk, it is important to raise a safeguarding alert according to your organisation’s local policy.

Approach

- **Listen very carefully and check you have understood the meaning behind the family's/carer's/friend or loved one's request.** People often have very real practical and psychological concerns about the process of dying when it relates to a family member or the person they care about. They may say "How long will this go on?", for example.
- At all times it is important that you convey compassion and caring and concern when talking to family members/people who are close to the patient. **Be gentle but direct in reflecting back what you have heard and clarifying what is being asked** – people often use vocabulary around assisted suicide that can make a specific meaning unclear.
- **Share clear information about the end of life process**, reassuring them that while there is much uncertainty and the moment of death is hard to predict, you will take steps to minimise any discomfort or distress. Explanation, discussion and communication about the end of life processes are all important aspects of enabling those close to the patient to come to terms with what is happening and maybe participate in care alongside the care team.
- **You may also wish to explore with the family/carer/significant others any perceived obligation to be present at all times.** They may value someone giving them 'permission' to take a rest, or to make arrangements with other significant others to rotate time spent by the bedside.
- During your conversation you should acknowledge the distress the family may be experiencing, and **provide an opportunity for them to express their emotions** – if that is culturally appropriate – about the situation.
- **As part of the discussion process you may wish to explore their perception of their loved one's care.** Are they seeing things the clinical team is missing during its assessments, or is this an expression of their own distress?
- **You may also wish to explore with the family or carer if they wish to revisit any perceived obligation to remain permanently at the bedside.** They may value someone giving them 'permission' not to be there at all times, to take a rest, or to make arrangements with other significant others to rotate time spent by the bedside.

- **Record their concerns, and the discussions, in the patient's notes.** This ensures continuity of care, and assists in sharing your insight gleaned from the family with the patient's medical practitioner and other health care providers. Refer to other services which compliment generalist care and offer additional support.
- **Be clear in the conversation that it is not legal to hasten death in the UK, and reinforce that the health care team will not make interventions towards this end.** You may wish to involve another health care professional who has the skills to support a sensitive discussion about the aims of care.

Information on additional resources to help you with your palliative and end of life care practice and communication with relatives and carers is included at the end of this publication.

Reflect and discuss

Talking with family members and significant others who may be in distress is part of the process of end of life care. Understanding their perspective and where they are 'coming from' will help you to deal with the range of emotions they may exhibit.

As a nurse or health or social care professional, you are responsible for ensuring patients receive the best possible care available. How can you ensure that your observations trigger an appropriate response from the wider multidisciplinary care team?

How do you act to make sure families and carers are given sufficient and appropriate time to express their fears and concerns?

Situations like these can also provide useful discussion points for you and your team to explore how you might respond in future and what lessons you can learn about the service you offer, and the care you provide. These dialogues offer an opportunity to debrief following stressful situations and scenarios and there are a number of resources at the end of this publication which can support your discussions.

Frequently asked questions

If a patient or their family asks, am I able to directly provide contact details or website addresses for organisations that promote or provide support for people wishing to commit suicide?

No. It is the RCN's view that it is inappropriate and potentially illegal to provide contact details or website addresses for organisations that promote or provide support for people wishing to commit suicide.

Under current UK law giving this kind of assistance may be seen as doing an act capable of encouraging or assisting the suicide or attempted suicide of another person.

Committing or attempting to commit suicide is not in itself a criminal offence. For there to be a prosecution there would have to be evidence not only that someone committed or attempted to commit suicide, but also that they were assisted or encouraged in some way.

If there were to be an investigation following such an attempt, the police and the prosecutor would look at whether or not this act (the act of providing information) was intended to encourage or assist suicide or an attempt at suicide.

The legal framework is slightly different in Scotland. However, while there is no specific statute against assisting suicide, it is currently the case that assisting or attempting to assist a suicide is likely to constitute a criminal offence; in the recent *Gordon Ross v Lord Advocate* (2016) case, the court again confirmed that it is "in accordance with the law" to criminalise those who assist others in their suicide.

I have personal views about assisted suicide. Can I talk about these views to patients or other members of the public in my care?

It is the RCN's view that it would be inappropriate to discuss your personal views on the matter of assisted suicide, assisted dying, or euthanasia with anyone in your care or their relatives or guardians. To do so may cause unnecessary distress or offence to those holding strong views contrary to your own.

If you are a registered nurse or midwife, the Nursing and Midwifery Council (NMC) *Code of Conduct* requires you to uphold the reputation of your profession at all times. If you are a health or social care support worker, you are governed by the codes of conduct of all UK countries – England, Wales, Scotland and Northern Ireland – which require that you maintain clear and professional boundaries in relationships with service users.

A member of my staff has reported a conversation about someone in their care contemplating asking a friend or family member to assist them to commit suicide. How do I respond?

There are a number of issues here that need to be explored, but your primary responsibility is to seek to maintain the individual's safety and well being as far as you are able.

Having a timely conversation and sharing this information with the medical practitioner responsible for the patient's care is necessary.

The expression of suicidal intention might be part of an underlying depression or an expression of concerns and fears relating to coping and the future. You should record the reported conversation, and consult your organisation's policies and procedures relating to risk management, incident reporting, and patient supervision.

Going forward, it may be appropriate to adopt a multidisciplinary approach to investigating the issue, and a case review may be in order.

A chronically ill patient in my care is talking about their plans for the end of their life – one of the team says we might need to assess the patient's mental capacity before preparing an advance care plan with them. What is meant by the term 'mental capacity'?

The laws in the UK around this term are complex. If the 'capacity' of someone in your care is in question, then it is a matter that will need to be resolved by appropriately trained staff acting in the best interests of the patient. If you are unsure, you should discuss with your line manager or the patient's medical practitioner.

The following summary should help you understand the law as it relates to capacity.

In England and Wales, the Mental Capacity Act 2005 provides a statutory framework for adults who lack capacity. In assessing a person's capacity there is a statutory presumption that the person has capacity unless the contrary is shown. The requirements of the Act affect health and social care professionals, other carers, and family members. The Act is supported by a Code of Practice which provides appropriate information and guidance to these individuals.

Section 2 of the act states that '...a person lacks capacity in relation to a matter if at the material time he is unable to make the decision for himself in relation to the matter, because of an impairment of, or a disturbance of, the mind or brain.'

In other words, a person's capacity must be assessed in relation to a specific decision that needs to be taken, not the person's ability to make decisions generally. In this way capacity may vary, depending on the nature of the decision to be taken. Where the impairment or disturbance of mind or brain is caused by a condition that is medically diagnosed, it is not the diagnosis itself that determines capacity but its impact on the person's decision making ability as described below.

Section 3(1) of the act provides that a person is unable to make a decision if he/she cannot:

- understand the information relevant to the decision
- retain that information
- use or weigh that information as part of the process of making the decision
- communicate his or her decision (whether by talking, using sign language or any other means).

In Wales, the *Mental Capacity Act 2005 (Independent Mental Capacity Advocates) (Wales) Regulations (2007)* define further the role of "independent mental capacity advocates" (IMCAs) and contain provision as to who can be appointed to act as an IMCA and as to an IMCA's functions when he or she has been instructed to represent a person in a particular case. The provisions about the IMCA's appointment and functions apply where the IMCA is instructed under sections 37 to 39 of the Act, or under regulations made by virtue of section 41 of the Act.

In Scotland, the Adults with Incapacity (Scotland) Act 2000 sets out the framework for assessing capacity and safeguarding those deemed to have impaired or lost capacity. It starts from the basic assumption that an individual has capacity, ensuring the need to prove on balance a lack of capacity before decisions can be made by others – whether a medical professional or a nominated proxy such as a welfare power of attorney.

The act states that a person is unable to make a decision for him/herself if, due to mental disorder or inability to communicate because of physical disability, they are incapable of:

- acting
- making a decision
- communicating decisions
- understanding decisions
- retaining the memory of decisions.

The Scottish Government has set out specific guidance to support health professionals in assessing capacity under the act (these are included in the references section of this publication). This is based on the core principle of the act that "all decisions made on behalf of an adult with impaired capacity must:

- benefit the adult
- take account of the adult's past and present wishes
- restrict the adult's freedom as little as possible while still achieving the desired benefit
- encourage the adult to use existing skills or develop new skills
- take account of the views of others with an interest in the adults welfare."

The Act also clearly states that medical treatment given to an incapacitated person must be designed to "promote physical or mental health."

In Northern Ireland, new combined mental capacity and mental health legislation came into force in May 2016, when the *Mental Capacity Act (Northern Ireland) 2016* became law. The overall principle of the act is 'autonomy' which ensures that individuals with mental capacity to make their own decisions about their health care, welfare and financial affairs will be allowed to do so.

All patients, regardless of their mental capacity, are unable to access assisted suicide in the UK as it is illegal. It is also worth noting that cognitive acuity can fluctuate with progressive illness and frailty and often hampers the patient's ability to have detailed and profound conversations about their end of life. If patients are asking for assisted suicide, yet their mental capacity is in doubt, you should stop and think about their ability to tolerate a more detailed exploration of the motivation behind this request.

A family has made comments which lead me to believe they have misinterpreted my care as deliberately helping someone to die. How should I respond to this?

It is important to make it clear that what you have done was part of an agreed package of care and was not intended to hasten death.

When delivering care there are numerous opportunities to explore and explain your role with the patient and their family. Communicating the care you give and what services you can

provide will be an important part of ensuring the person receives effective care.

Patients, those who are important to them, and inexperienced health practitioners can sometimes view a particular action as the 'final' one and make a causal link where none exists.

The RCN would recommend gently exploring, at the earliest opportunity, what the individual understands about your role and what particular therapeutic intervention prompted their comment, as you may have misinterpreted what was actually meant.

You could start by talking through the care delivered over the last few days, using the care plan and any advance decision to refuse treatment as a guide for identifying how the patient's needs and wishes were met.

This could lead to a discussion of the specific aspects of care, including symptom management and 'active' interventions. If you feel able, you may wish to explore the individual's notion of the 'final act' or the 'last injection'. Having sensitively explored any statements from the family, it may then be appropriate to make it clear that it is illegal for nurses and other health professionals to participate in, or to assist in hastening the death of another person.

You will need to ensure that you carefully document any such conversations and their outcome to provide continuity of care.

My friend/relative has asked me to accompany them abroad to an assisted suicide clinic. Although I am a nurse, I will be accompanying them as a friend/relative. Is this OK?

You are becoming involved in an act capable of encouraging or assisting the suicide or attempted suicide of your friend/relative, and this is breaking the law. Although you say that you are doing this as a friend or relative, and not a nurse, this may not be the interpretation put on your actions by the prosecuting authorities. As a registered nurse you are also bound by the requirements of the NMC *Code* which states that you must always act lawfully, whether those laws relate to your professional practice or personal life.

A resident in the care home that I work at has been using the communal computer to search the internet for organisations associated with assisted suicide. What action should I take?

There are a number of issues here that need to be explored, but your primary responsibility is to seek to maintain the individual's safety and wellbeing as far as you are able.

Searching the internet for information on assisted suicide may indicate an intention to commit suicide, or to assist another in their suicide.

You may wish to sensitively approach the resident and indicate you are aware they have been using the computer to search for organisations associated with assisted suicide and offer to discuss their reasons for doing this. In this way you may be able to find out the reasons behind this action, and move towards having a conversation during which you can examine the resident's perceptions and current situation.

You should inform the care home manager, the patient's medical practitioner, record your findings and consult your organisation's policies and procedures relating to risk management, incident reporting and patient supervision.

A patient wishes to discharge himself from our care and has made it clear that he intends to seek assisted suicide. What can I do?

Patients with capacity have the right to refuse care and to discharge themselves from services. You should consult your organisation's guidance on discharge, and document the patient's stated intention, offer to review potential support and care options, and inform wider members of the multidisciplinary team.

Trying to engage the patient, and those important to them, in conversation (as outlined earlier in this publication) may be beneficial.

It might be that you have the opportunity, experience, and confidence to explore the patient's expressed intentions further, and where possible, offer follow-up support in the community via their GP, community mental health team or a specialist palliative care team.

Inform the patient's GP and/or the out-of-hours service if you feel the patient is an adult at risk. Consider whether you may need to raise a 'safeguarding' alert.

Glossary of terms

Advance care plan (ACP) is a process of discussion between an individual and their care providers irrespective of discipline. The difference between ACP and planning more generally is that the process of ACP is to make clear a person's wishes and will usually take place in the context of an anticipated deterioration in the individual's condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others (DH, 2007).

Advance decision to refuse treatment (England and Wales). The courts have recognised that adults have the right to say in advance that they want to refuse treatment if they lose capacity in the future – even if this results in their death. A valid and applicable advance decision to refuse treatment has the same force as a contemporaneous decision. This has been recognised by the common law for many years and it is now set out in the Mental Capacity Act. Sections 24–26 of the act set out when a person can make an advance decision to refuse treatment. This applies if the person is 18 or older, and they have the capacity to make an advance decision about treatment (DH, 2008).

Advance statements (Scotland) set out the future wishes of a competent person, specifically around treatments for mental disorders, should their own decision-making process become impaired. However, while Scottish advance statements relate only to treatment under the Mental Health (Care and Treatment) (Scotland) Act 2003, the Adults with Incapacity (Scotland) Act 2000 also states that anyone authorised to make decisions on behalf of someone else, as a result of that person's impaired capacity, must have regard to their current and past wishes. As such, a statement of treatment wishes (known as an "advance directive" or "living will") written by someone over 16 years of age when competent could be used to determine those past wishes with regards to more general medical treatments.

Assisted suicide refers to when an individual is provided with the means and assistance (for example using drugs, equipment, and so forth) to commit suicide by another person or persons. The term assisted suicide should be distinguished from euthanasia.

Euthanasia means the taking of direct action by a doctor to end a patient's life. The term 'assisted dying' is often used to encompass either or both 'assisted suicide' and 'euthanasia'.

Health-promoting palliative care recognises that health, wellbeing and quality of life is important when facing death. Focused on empowering patients, health-promoting palliative care sets out to ensure that people in the last months and weeks of life are able to enjoy periods of good health and wellbeing, and can share these with family, friends and wider community members.

Physician-assisted suicide involves a doctor prescribing a lethal drug which is administered by a patient or by a third party, such as a nurse or relative (DH, 2003).

Safeguarding is an umbrella term used to describe the various statutory systems and processes in place to protect vulnerable adults or children and young people from abuse, harm or exploitation.

References and further reading

- All Wales Palliative Care Planning Group (2008) *Report to Minister for Health and Social Services on Palliative Care Services – Sugar Report*, Cardiff: WAG. Available at: www.wales.nhs.uk/documents/palliativecarereport.pdf
- All Wales Palliative Care Planning Group (2008) *Implementation of Palliative Care Report: Palliative care services funding 2008 to 2009*, Cardiff: WAG.
- Care Council for Wales (2015) Code of professional practice for social care, Cardiff: CCW. Available at <http://www.ccwales.org.uk/code-of-professional-practice/> (Accessed 09.08.16).
- Care Quality Commission (2016) *A different ending: end of life care review*, Newcastle: CQC.
- Chochinov HM (2007) Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care, *British Medical Journal*, 335 (7612,) pp.184-187.
- Chochinov HM, Hassard T, McClement S, Hack T, Kristianson LT, Harlos M, Sinclair S and Murray A (2008) The patient dignity inventory: a novel way of measuring dignity-related distress in palliative care, *Journal of Pain Symptom Management*, 36(6), pp.559-571.
- Department of Health (2007) *Advance care planning: a guide for health and social care staff*, London: DH.
- Department of Health, Social Services and Public Safety for Northern Ireland (2010) *Living Matters, Dying Matters: A Palliative and End of Life Care Strategy for Adults in Northern Ireland*, Belfast: DHSSPS.
- Director of Public Prosecutions (2010) *Policy for prosecutors in respect of cases of encouraging or assisting suicide*, London: The Crown Prosecution Service. Available at: www.cps.gov.uk
- End of Life Care Coalition (2016) *On the brink. The future of end of life care report*. Available at: <http://endoflifecampaign.org/wp-content/uploads/2016/02/End-of-Life-Report-WEB.pdf> (Accessed 07.06.16).
- General Medical Council (2015) *When a patient seeks advice or information about assistance to die*, London: GMC.
- General Medical Council (2010) *Treatment and care towards the end of life: good practice in decision making*, London: GMC.
- Hudson P, Schofield P, Kelly B, Hudson R, Street A, O'Connor M, Kristjanson L, Ashby M and Aranda S (2006) Responding to desire to die statements from patients with advanced disease: recommendations for health professionals, *Palliative Medicine*, 20, pp.703-710.
- Machin V (2003) *Churchill's medicolegal pocketbook*, Oxford: Churchill.
- Marie Curie UK (2016) *Hiding who I am – the reality of end of life care for LGBT people*, London: Marie Curie. Available at: <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2016/reality-end-of-life-care-lgbt-people.pdf> (Accessed 05.08.16).
- McCarthy J, Donnelly M, Dooley D, Campbell L and Smith D (2010) *Ethical framework for end-of-life care*, Dublin: Irish Hospice Foundation. Available at: www.hospicefriendlyhospitals.net/ethics
- Mental Welfare Commission for Scotland (2014) *Advance statement guidance*, Edinburgh: Mental Welfare Commission for Scotland. Available at http://www.mwscot.org.uk/media/128044/advance_statement_final_version_jan_2014.pdf (Accessed 09.08.16).
- National End of Life Care Programme (2011) *Capacity, care planning and advance care planning in life limiting illness: a guide for health and social care staff*, Leicester: NHS National End of Life Care Programme. Available at: www.endoflifecareforadults.nhs.uk.
- National Institute for Health and Care Excellence (2015) *Care of dying adults in the last days of life: NICE guidelines [NG31]*, London: NICE. Available at www.nice.org.uk.
- Northern Ireland Social Care Council (2015) *Standards of Conduct and Practice for Social Care Workers and Social Workers*, Belfast: NISCC.
- Nursing and Midwifery Council (2015) *Code: standards of conduct, performance and ethics for nurses and midwives*, London: NMC.
- Parliament (2009) *Coroners and Justice Act*, London: TSO.
- Parliament (2005) *Mental Capacity Act*, London: TSO.
- Parliament (1966) *Criminal Justice (Northern Ireland) Act*, London: TSO.
- Parliament (1961) *Suicide Act*, London: TSO.

- Parliamentary and Health Service Ombudsman (2015) *Dying without dignity. Investigations by the Parliamentary and Health Service Ombudsman into complaints about end of life care*, London: PHSO. Available online at http://www.ombudsman.org.uk/_data/assets/pdf_file/0019/32167/Dying_without_dignity_report.pdf (Accessed 07.06.16).
- Royal College of Nursing (2009) *Assisted suicide: an overview of the debate*, Policy Briefing 04/2009, London: RCN.
- Royal College of Nursing (2010) *First steps for health care assistants*, London: RCN.
- Royal College of Nursing and the Royal College of General Practitioners (2011) *End of life care patient charter: a charter for the care of people who are nearing the end of their life*, London: RCN and RCGP.
- Royal College of Physicians (2016) *End of Life Care Audit – Dying in Hospital, National report for England 2016*, London: RCP. Available online at <https://www.rcplondon.ac.uk/news/new-rcp-end-of-life-care-audit-shows-steady-progress-care-dying-people> (Accessed 07.06.16).
- Scottish Parliament (2003) *Mental Health (Care and Treatment) (Scotland) Act*, Edinburgh: TSO.
- Scottish Parliament (2000) *Adults with Incapacity (Scotland) Act*, Edinburgh: TSO.
- Skills for Health (2013) *Code of Conduct for Healthcare Support Workers and Adult Social Care Workers in England*, London: SfH. Available online at <http://www.skillsforhealth.org.uk/images/services/code-of-conduct/Code%20of%20Conduct%20Healthcare%20Support.pdf> (Accessed 07.06.16).
- The Scottish Government (2016) *Do not attempt cardiopulmonary resuscitation (DNACPR) – integrated adult policy. Decision making and communication*, Edinburgh: TSG. Available online at <http://www.gov.scot/Resource/0050/00504976.pdf> (Accessed 08.09.16).
- The Scottish Government (2015) *Strategic Framework for Action on Palliative and End of Life Care 2016-2021*, Edinburgh: TSG. Available online at <http://www.gov.scot/Resource/0049/00491388.pdf> (Accessed 10.10.16).
- The Scottish Government (2011) *Palliative and end of life care in Scotland*, Edinburgh: Directorate for Health and Healthcare Improvement Quality Division Chief Executive Letter (CEL 2)(27 January 2011).
- The Scottish Government (2010) *Scottish Government's healthcare quality strategy for NHS Scotland*, Edinburgh: TSG.
- The Scottish Government (2009) *Code of Conduct for Healthcare Support Workers*, Edinburgh: TSG. Available online at <http://www.gov.scot/resource/doc/288853/0088360.pdf> (Accessed 07.06.16).
- Social Care Institute for Excellence and Department of Health (2008) *Advance decisions to refuse treatment: a guide for health and social care professionals*, London: DH.
- Welsh Government (2015) *Together for Health: End of Life Care Annual Report 2015*, Cardiff: WAG.
- Welsh Government (2013) *Together for Health – Delivering End of Life Care: a Delivery Plan up to 2016 for NHS Wales and its Partners*, Cardiff: WAG.
- Welsh Government (2011) *The Code of Conduct for Healthcare Support Workers in Wales*, Cardiff: WAG.

Resources to improve end of life care practice

NICE guidelines [NG31]

In December 2015, NICE published its *Care of dying adults in the last days of life guidelines* [NG31]

The NICE guidelines include recommendations alongside tools and resources, which are available at <https://www.nice.org.uk/guidance/ng31/chapter/Recommendations-for-research>.

Department of Health Consensus Statement on information sharing and suicide prevention

In 2014 the Department of Health in England and eight professional organisations published a consensus statement on information sharing and suicide prevention. The statement addresses the difficult balance health professionals can face between respecting client confidentiality while doing everything possible to reduce the risk of suicide and supporting family members.

The publication is available online at www.gov.uk/government/uploads/system/uploads/attachment_data/file/271792/Consensus_statement_on_information_sharing.pdf.

Scottish Government's Strategic Framework for Action on Palliative and End of Life Care

The Scottish Government recently published its *Strategic Framework for Action on Palliative and End of Life Care 2016-2021* which outlines the actions that need to be taken to ensure that by 2021 everyone who needs palliative care will have access to it. The framework will also work to drive a new culture of openness about death, dying and bereavement. You can access the framework at <http://www.gov.scot/Resource/0049/00491388.pdf>.

The Scottish Palliative Care Guidelines are available at www.palliativecareguidelines.scot.nhs.uk

Good Life, Good Death, Good Grief is working to make Scotland a place where there is more openness about death, dying and bereavement. The organisation provides a range of online resources, which can be found at www.goodlifedeathgrief.org.uk.

NHS Education for Scotland's website aims to support health care staff who are working with patients, carers and families before, at, and after death. It provides key information on the clinical legislative and practical issues involved; visit www.sad.scot.nhs.uk.

A further useful resource is NHS Inform which provides an information resource for the public in Scotland. The website's palliative care zone, which can be found at www.nhsinform.co.uk/palliativecare, provides signposting to help and services as well as resources on planning for the future and planning for death and bereavement.

Welsh Government End of Life Care Delivery Plan

In 2014, the Welsh Government set out its expectations of NHS Wales to work with partners, in particular the hospice and social care sector, to reduce inequalities in end of life care.

Resources provided by the Welsh Government included:

- A delivery plan up to 2016 for NHS Wales and its partners, available at <http://gov.wales/docs/dhss/publications/130416careen.pdf>
- End of Life Care Annual Report 2015, available at <http://gov.wales/topics/health/nhswales/plans/end-of-life-care/?lang=en>.

Health care professionals working in the palliative care field are also referred to the *Palliative Care in Wales* website at <http://wales.pallcare.info/>.

NHS Wales has a microsite dedicated to the Mental Capacity Act 2005 and related legislation and guidance, which can be found at <http://www.wales.nhs.uk/sites3/page.cfm?orgid=744&pid=36239>.

End of Life Care for All – e-ELCA

e-Learning For End of Life Care for All (e-ELCA) is an award winning e-learning programme providing national quality assured online training content for the health care profession. The e-ELCA sessions have been highlighted as a resource to help with the implementation of NICE guidelines published in December 2015 on improving care for people in their last days of life (*Care of Dying Adults in the Last Days of Life* [NG31]).

There are over 150 highly interactive sessions which are grouped into eight modules:

- advance care planning
- assessment
- communication skills
- symptom management

- social care
- bereavement
- spirituality
- integrated learning.

All resources can be accessed at www.e-lfh.org.uk.

Dying Matters Coalition

In 2009 the National Council for Palliative Care (NCPC) set up the Dying Matters Coalition to promote public awareness of dying, death and bereavement. Members include organisations across the NHS, voluntary and independent health and care sectors (including hospices, care homes and charities supporting old people, children and bereavement), a wide range of faith organisations, academic bodies, the legal profession and the funeral sector.

The coalition's mission is to help people talk more openly about dying, death and bereavement, and to make plans for the end of life, encouraging people to talk about their wishes towards the end of their lives.

The Dying Matters website contains materials that will help you start those conversations. Resources include DVDs, posters, awareness packs and leaflets. The website also contains information created for people approaching their end of life, and their carers, relatives and friends.

The Dying Matters organisation provides a template designed to support people to think about and prepare their Preferred Priorities for Care (PPC). The template is available at http://www.dyingmatters.org/sites/default/files/preferred_priorities_for_care.pdf.

Visit www.dyingmatters.org.

Gold Standards Framework Organisation

The Gold Standards Framework (GSF) is a systematic evidence-based approach to optimising the care for patients nearing the end of life, and helping people to live well until the end of life, whatever their illness or the setting.

The GSF's website www.goldstandardsframework.org.uk contains details on training programmes for generalist frontline staff, together with toolkits and other resources to support the implementation of GSF.

Change Cancer Series – Palliative Care: End of Life Care and Bereavement

This is a useful resource for those caring for people with a learning disability and people who find reading hard. Visit www.changepeople.co.uk.

Spirituality in Nursing Care

The RCN has published a guide to enable nursing staff to address questions about the spiritual part of care. You view the RCN's pocket guide to spirituality in nursing care at https://www2.rcn.org.uk/_data/assets/pdf_file/0008/372995/003887.pdf.

Skills for Care

Skills for Care work closely with organisations that employ social care workers together with people who use services, carers and other key partners, to develop effective tools and resources that meet workforce development needs.

The Skills for Care publication *Common core principles and competences for end of life care* is available at: <http://www.skillsforcare.org.uk/Documents/Topics/End-of-life-care/Common-core-principles-and-competences-for-social-care-and-health-workers-working-with-adults-at-the-end-of-life.pdf>.

Conducting difficult conversations

The National Council for Palliative Care (NCPC) has produced a series of publications designed to inspire confidence and help health and social care professionals start and continue important conversations with people living with a range of conditions. You can find out more at www.ncpc.org.uk/difficult_conversations.

An extensive range of information, audio and video resources on how to conduct difficult conversations can also be found online at the RCN's dedicated *End of life care* website at <http://rcnendoflife.org.uk/communication/>.



Royal College of Nursing

The RCN represents nurses and nursing, promotes excellence in practice and shapes health policies

2nd edition December 2016

Review date December 2018

RCN Online

www.rcn.org.uk

RCN Direct

www.rcn.org.uk/direct

0345 772 6100

Published by the Royal College of Nursing

20 Cavendish Square

London

W1G 0RN

020 7409 3333

Publication code: 005 822

ISBN: 978-1-910672-67-9