

Responding to desire to die statements from patients with advanced disease: recommendations for health professionals

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It is not uncommon for patients with advanced incurable disease to express a desire to hasten their death. Health professionals often have difficulty responding to such statements, and find it challenging to ascertain why these statements are made. Health professionals may struggle to determine whether a 'desire to die' statement (DTDS) is about a request for hastened death, a sign of psychosocial distress, or merely a passing comment that is not intended to be heard literally as a death wish. Given the lack of guidelines to assist health professionals with this issue, we have prepared multidisciplinary recommendations for responding to a DTDS, underpinned by key principles of therapeutic communication and a systematic review of empirical literature. Where the relevant literature was lacking, the recommendations were drafted by the authors (clinicians and/or academics from the following disciplines: nursing, medicine, psychiatry, psychology, sociology, aged care and theology), based on their expert opinion. Multiple drafts of the recommendations were circulated to the authors for refinement until consensus was reached. Strategies for advancing the evidence base for the maturation of guidelines in this area are offered. *Palliative Medicine* 2006; **20**: 703–710

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Introduction

It is not unusual for health professionals caring for patients with life-threatening advanced disease to be confronted by a patient's expression of a desire for a hastened death.¹ These statements are described by a variety of terms, such as 'death talk' or 'suicide talk', and are referred to in the literature as 'desire to die statements' (DTDSs).^{2,3} 'Desire to die' statements are thought to underlie suicidal ideation; however, not all DTDSs fall into this category, they may have other foundations not necessarily associated with a specific desire to expedite the dying process.^{4–6}

Health professionals have an obligation to respond professionally and compassionately to DTDSs,⁷ assessing each DTDS to identify any treatable problems or

concerns.^{5,8,9} However, DTDSs can provoke concern and confusion for health professionals, even those with many years experience, as they try to determine the basis of these statements and an appropriate response.^{2,8–11} Further, a DTDS may not necessarily be explicit, making appropriate responses even more challenging.¹¹

The purpose of this article is to provide health professionals from nursing, medical and allied health disciplines, with recommendations on how to respond when confronted with a DTDS. This multidisciplinary approach offers a framework that is consistent across health disciplines, and is supported by principles of therapeutic communication. The article concludes with several strategies for the advancement of guidelines to enhance the future care for patients who make a DTDS. It is not the purpose of this article to engage in a debate about the moral dimensions of euthanasia or suicide, and whether a DTDS might be considered rational or reasonable in some circumstances. Rather, it is hoped that health professionals would be assisted by these recommendations to respond to a DTDS with

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compassion and professionalism, regardless of their stance on such debates.

Why guidelines are needed

Although there are some discipline-specific suggestions for responding to clear requests for euthanasia or physician-assisted suicide, there is a paucity of evidence-based strategies to guide health professionals' responses to a DTDS.^{12,13} Recommendations are needed on how to respond to DTDSs in patients with advanced disease, so that health professionals are adequately prepared for this aspect of their role.^{5,14} Appropriate therapeutic responses to a DTDS is one of the most controversial ethical issues in healthcare.¹⁵ Without guidance, health professionals may offer inappropriate responses to patients who make DTDSs, consequently compromising the quality of care.

Patients' wishes about end-of-life care should be assessed routinely with the patient and family soon after a diagnosis of life-threatening illness is made; this assessment should be regularly reviewed.^{16–18} Research shows, however, that many health professionals find it difficult to assess and respond to psychosocial and spiritual issues in the context of advanced disease. There is a tendency to avoid discussing difficult issues, especially prognosis, for fear of diminishing hope.¹⁹ Health professionals may believe that by exploring issues, such as desire for hastened death, they will unleash strong emotions that are difficult to contain.²⁰ They fear it may be psychologically damaging to the patient, as well as time-consuming and emotionally draining.²⁰ They may also feel uncertain about the 'correct timing' of such discussions, not wishing to introduce such a topic when the patient is already dealing with issues of diagnosis and prognosis.

Furthermore, many health professionals, such as doctors, nurses and social workers, often feel inadequately prepared to respond to a DTDS.^{2,8,12,21–23} Nurses, for example, are commonly confronted with DTDSs,^{24–26} and fearing they may say the wrong thing in response,²⁷ may instead say nothing.²¹ Nurses may also keep their experiences of DTDSs to themselves,²⁵ based on anxieties about professional or legal sanction.²⁸ Others lack knowledge and skills about the broader context of DTDSs.²⁹ When spiritual issues are discerned, not all members of the health care team have the capacity to respond appropriately,³⁰ while others believe they should not delve into a patient's private beliefs.³¹ Although position statements regarding end-of-life decision making are available,^{32,33} these statements vary in their quality and practical application.^{34,35}

Health professionals' attitudes towards psychosocial issues have a significant impact upon the way they communicate with patients.³⁶ Some health professionals may feel it is not their role to deal with DTDSs; hence, they may discourage or ignore statements of this type.

Some doctors, for example, unfortunately believe that discussions of psychosocial matters are not their responsibility.³⁷ Health professionals often assume that patients will disclose psychological concerns;²⁰ however, research shows that only a minority of patients (25%) discuss these issues unprompted.³⁷ Patients may believe that it is: (a) inappropriate to trouble the health professional with their concerns; (b) that there is not enough time; (c) the health professional would be unwilling or unable to help;³⁸ or (d) that their feelings are unreasonable or that their expressed desire suggests they are not coping with their illness.²⁰ All of these factors may play a role in patients not disclosing their desire to die to health professionals.

There are also a number of ways in which both patients and health professionals can 'block' the disclosure of psychological distress, especially concerns regarding death. These include ignoring the statement,³⁹ monopolizing the conversation by focusing on biomedical or physical issues,⁴⁰ changing the topic, particularly reverting to the physical concerns,⁴¹ and offering premature or false reassurance.²⁰

The challenges of responding to DTDSs in the palliative care setting are compounded by the fact that a considerable proportion of patients are also confronted by anxiety, depression and loss of function, the majority facing death within weeks to months.⁴² Hence, DTDSs may be viewed as reasonable reactions to such unfavourable circumstances. They may also be regarded as transient comments not warranting comprehensive exploration. By contrast, in a health care setting where curative treatment is the norm, a DTDS may be viewed as an aberration.

An additional challenge for health professionals is that the desire for hastened death may fluctuate over time.^{6,43} This may make it difficult for health professionals to allocate time and resources to accurately assess the basis and intent of such statements.

Health professionals may assume that a DTDS is made because a patient is significantly depressed. This is a reasonable concern given that 10–25% of palliative care patients have been identified as clinically depressed.² DTDSs may also be linked to missed or inadequate information about health care options.⁴⁴ Through dialogue, it may emerge that the cause of the DTDS is less problematic than anticipated. Nonetheless, signs of depression demand comprehensive assessment because depression is frequently undiagnosed and under-treated.^{44,45}

Health professionals may be further challenged by a DTDS due to concerns regarding a patient's potential suicide. Despite warning messages preceding 80% of suicides, these messages are commonly ignored or discounted.²¹ However, there is no evidence that asking about suicidal thoughts will elicit suicidal behaviour in

someone who has not previously considered the possibility of suicide.⁴⁵ Health professionals can engage in meaningful communication when responding to a DTDS by inquiring about the patient's emotional state, conveying a willingness to talk about their distress, and helping them identify the motivations for the request to die.⁴⁶

Health professionals may also be unsure about whether or not they ought to discuss a patient's DTDS with a colleague. Patients should be made aware from the outset about issues regarding confidentiality and disclosure of information to health professionals. They should be advised that within the context of multidisciplinary care, health professionals usually share patient information based on the principle that a team approach to decision-making is more likely to result in optimal care.²⁸ Suicidal wishes should be documented and communicated to relevant members of the multidisciplinary team.^{21,34} Health professionals need to adopt an impartial stance if a patient's views on hastened death are contradictory to their own; they should not abandon, judge or chastise patients.

Methods

Given the lack of empirical studies underpinning guidelines for responding to DTDSs in this population,¹³ a framework for responding to DTDSs was constructed based upon the principles of therapeutic communication and consensus expert opinion. Consensus opinion incorporated published recommendations, based on a systematic review of the literature,¹³ for responding to DTDSs that seemed appropriate to the panel (the authors of this paper). This panel comprised clinicians and/or academics from the following disciplines: nursing, medicine, psychiatry, psychology, sociology, aged care and theology. The panel discussion complemented the published recommendations by developing additional responses and strategies based on panel members' professional experience in witnessing and responding to DTDSs, and their insight into the literature in this area. Multiple drafts were circulated over a two-year period until consensus was reached. Two groups of postgraduate palliative care nurses and doctors also provided feedback.

Therapeutic communication principles for responding to a DTDS

Due to the significant challenges that might confront health professionals related to DTDSs, the suggested framework for responding to DTDSs is based on the principles of therapeutic communication, and is supported by high level evidence.⁴⁵ Evidence from systematic reviews of randomized, controlled, trials with people with cancer show that:

- interactions that convey empathy for the patient's distress and active listening assists psychological adjustment;
- provision of comprehensive information about what to expect in the future promotes psychological well-being;
- an opportunity to discuss feelings with a health professional reduces psychosocial distress; and
- where relevant, referral to health professionals who specialize in management of psychosocial distress can have favourable outcomes.

DTDSs warrant careful attention and open, sensitive, communication in the clinical setting.^{6,32} Core therapeutic communication approaches provide a solid framework for exploring end-of-life issues and responding to DTDSs.¹⁷ Box 1 provides an outline of these strategies, other useful resources can be found elsewhere.^{47,48} It is recommended, therefore, that health professionals use this framework for specific questions and responses related to DTDSs.

Recommended health professional responses to a DTDS

We have argued that seeking to understand the meaning behind a DTDS is crucial to formulating a professional response and appropriate interventions.⁴⁹ Accordingly, we have prepared a two-phase approach, based on four broad categories,¹³ for recommended responses and questions to be considered by health professionals when they first encounter a DTDS (see Box 2). Phase I prompts health professionals to take time to explore the background to the DTDS before offering strategies or providing detailed information. In Phase II, the health professional considers broader information and initiates preliminary intervention strategies.

Where recommendations are based on published expert opinion, relevant authors are cited. Other recommendations come from the panel. Comments in quotation marks are suggested statements and questions which health care professionals may consider using.

It should be noted that we would not encourage health care professionals to ask these questions in one consultation. A conversational approach within an unhurried, trusting atmosphere is recommended. Moreover, we do not recommend a formulaic and prescriptive approach to responding to DTDSs – we encourage health professionals to view the following statements/phrases as examples only.

It is also important to emphasize the need for a response by health professionals to the wish to hasten death that aims to sensitively explore and come to an understanding of the often complex nature of the patient's concerns. Such exploration and understanding can lead to an appreciation of the appropriate therapeutic strategies and clinical approaches that aim to address

Box 1 Responding to emotional cues: general recommended principles (adapted from Ref. 45)

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1. *Be alert to your own responses*
 Adopt an open posture; be aware of your own emotional response at each stage of the conversation
 Be aware that your response can shape the communication; eg, if you convey a sense of shock or bewilderment, impatience or your own feelings of futility, this may have a negative effect or it may limit the conversation to follow
 Monitor your attitudes and responses to DTDSs; seek help from colleagues or a supervisor if necessary
 Show regard for the person by your verbal and non-verbal behaviour
 2. *Be open to hearing concerns*
 Ask questions that gently probe emotional concerns
 Be alert to verbal and non-verbal signs of psychological distress
 Encourage the person, by sensitive prompting where necessary, to express their feelings
 Listen actively without interrupting, seek clarification of feelings and concerns
 Acknowledge the feeling/s being expressed without needing to actively support the desire to die: try to match the words you use with the level of emotion the person is experiencing
 Use silence appropriately; do not rush to fill gaps in the conversation
 Sit quietly through tears
 Express empathy, both by your verbal and non-verbal responses
 Acknowledge there are individual differences in patients' emotional responses to the impact of life-threatening illness
 3. *Assessing the potential contributing factors*
 Assess whether the person has appropriate social support
 Assess type and level of formal assistance and/or referral/s that may be required (eg, psychological, informational resources)
 Assess for psychological distress (eg, depression/anxiety) and/or existential distress
 Assess for delirium, cognitive change and competence
 Assess level of understanding regarding goals of care and treatment options
 Assess for unrelieved physical symptoms
 Assess for interpersonal factors (eg, family conflict, conflict with clinical staff)
 4. *Responding to specific issue/s*
 Address potentially reversible causes (as discerned from assessment) and develop plan of management
 Commence planning strategies (eg, referral, another meeting) for issues that cannot readily be resolved
 5. *Concluding the discussion*
 Summarize main points of discussion; checking your perceptions with the patient's perceptions
 Ask if there is anything else the patient wants to discuss or if they have any other questions to raise
 Offer assistance to discuss the patient's situation with others, eg, in a family meeting
 Indicate your availability for contact to address any questions or concerns and arrange for further appointment to review situation
 Explain that it is important for you to let the other members of the treatment team know about this discussion and reassure them that it will be treated in the strictest confidence within the team
 6. *After discussion*
 Document discussion in medical records
 Advise other members of the treatment team, so they know your perceptions of the person's emotional state and can assist with follow up and/or referrals
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these concerns. The approach required is one that seeks to understand, rather than just act upon the request. This involves an engagement in communication with the patient. The aim is to (a) explore issues underpinning the statements, (b) identify the critical clinical issues, and

(c) discuss the interpersonal factors involved. Such sensitive communication might help to uncover the significance of the DTDS for the patient, and whether the statement is an expression of anger, despair, hopelessness or other forms of distress. Listening to the patient's reasons for making a DTDS can enable the health professional to mobilize appropriate interventions. Thus, the recommended approach is one where the patient who expresses a DTDS has ongoing communication and follow-up with a health professional with skills in therapeutic communication. This would include the capacity for referral to specialist services, such as psychology and psychiatry if required.

Limitations and future guideline development

These recommendations were developed using a comprehensive, three-stage, process of a systematic review of the literature, recommendations developed by a multidisciplinary panel complemented by published expert opinion, then multiple refinement to reach consensus. However, we encourage further testing and refinement of these recommendations, as there are several limitations. For example, the grey literature was not searched and articles not published in English were excluded. Moreover, the recommendations are based on consensus expert opinion and this does not meet the requirements of optimal guideline development processes.⁵⁰ However, we contend that, at present, there is insufficient research to use standard approaches for guidelines in this area. As demonstrated, there is an absence of intervention studies and minimal descriptive work upon which to base the development of these recommendations into formalized guidelines.

An additional limitation is that some readers may find the presentation of the recommended responses via the Box format to be somewhat limited. Our purpose in presenting the phrases and statements in this way is to allow for ready referencing. We also wish to reinforce that the example responses are not intended to be fixed or prescriptive. They are based on an assumption that health professionals working with people who are facing life-threatening or terminal illness require training in therapeutic communication to maximize their ability to support patients who express a desire to hasten death.

Attention to the future research related to a desire for hastened death should aid in the refinement of the recommendations.¹³ As an initial step, the appropriateness of these recommendations should be rated by health professionals, patients with advanced incurable disease, and their family carers. Future research should also include randomized, controlled, trials or quasi-experimental methods, in combination with qualitative methods, in order to test the implementation of these recommendations in the clinical setting.

Box 2 Recommended example phrases and questions (from the literature and expert opinion) when responding to a desire to die statement (DTDS)

Key concerns	Phase I: Assessing the nature of a DTDS – the initial response	Phase II: Assessing factors that may be contributing to the DTDS and preliminary interventions
1. Current feelings or fears	<p>"I want to try to do everything I can to work with you and provide you with the best care I can offer"⁵¹</p> <p>"Sometimes people feel so overwhelmed by things that they feel everything is 'just too much', would you say that you have felt like that lately?"⁴⁵</p> <p>"How does the future seem to you now? Have you found it hard to feel you can keep going lately? Do you feel that things will get any better than they are now?"⁴⁵</p> <p>"Can you tell me about the things that frighten or concern you the most at the moment?"⁴⁴</p> <p>"Some people make this statement when they're feeling really 'down'; then when circumstances change they feel differently. What do you think things might look like tomorrow?"</p> <p>"Sometimes when people have been sick they can feel like they are on their own or even feel lonely. How have you been lately? Do you feel this way?"⁵²</p> <p>What have you been able to get interested in lately? What do you find that you can get involved in that interests you or you can enjoy?</p> <p>Do you feel this (desire to die) more so at any particular time of the day or night, eg, when your visitors have left or in the early hours of the morning or when you first wake up?"</p> <p>"Do you feel this (desire to die) more so at any particular time of the day or night, eg, when your visitors have left or in the early hours of the morning or when you first wake up?"</p> <p>"Is this feeling there all the time or does it 'come and go'?"</p>	<p>Is the patient fully informed about their disease and prognosis?</p> <p>Is the patient competent? (Make appropriate referral if patient consents)</p> <p>Is the patient aware of available resources, eg, referral to another member of the multidisciplinary team?</p> <p>Is the patient aware that they can be cared for at a site of their choosing?</p> <p>Suggest the patient may like to write down their concerns (with assistance if necessary) so the team can focus more clearly on the patient's feelings at this time.</p> <p>Reassure the patient that you want to try to do everything possible to provide them with the best.⁴⁶</p> <p>Reassure the patient that the role of the team is to offer the utmost support.</p> <p>If feelings of distress have been identified, acknowledge these feelings and gently ask the patient whether they want to talk about it further.</p> <p>Recognition of religious/spiritual coping strategies relevant to the patient's experience and beliefs.⁵³</p> <p>Discuss with patient and family the possibility of adjusting visiting times to cover the more intense periods of loneliness and isolation.</p> <p>Are there reversible symptomatic issues?</p>
2. Suffering distress – physical, spiritual, psychosocial or existential)	<p>"What do you feel could be improved in your care and treatment?"</p> <p>"Sometimes, going through such times, some people feel disappointed in their beliefs or faith or feel like people important to them don't understand: have you felt this way? Can you describe those feelings?"</p> <p>"Often when people are coping with a severe illness, they think a lot about their past and the life they have had. Have you found yourself thinking about these things?"</p> <p>Some people give a lot of thought to their death and how it might be for them as that time draws closer – how about you?"</p> <p>"Are there particular things your feel concerned about?"</p> <p>"Can you tell me about how others have reacted to you being ill like this... who would you say understands best what you are going through?"</p> <p>"Could you tell me about the things that you most want to do at this point in your life, the things that you value the most?"³⁰</p>	<p>Will the future be more positive if the patient is advised that the focus of care will be on relief of pain and suffering?</p> <p>Has the topic of sedation been explored?</p> <p>Are there other ways of giving the patient more control over the time of death, eg, withdrawal of current treatments or assurance that no unwanted life prolonging measures will be taken?</p> <p>Is the patient depressed or confronted by other major psychiatric illness? (Make appropriate referral if patient consents).</p> <p>Conduct standard holistic assessment including family issues, spiritual issues.</p> <p>Is the patient afraid of dying alone, or without familiar carers around them?</p> <p>A DTDS may reflect the patient's perception of losing control. If so, what would assist the patient in maintaining control over this final phase of their life?</p> <p>Identify the most appropriate person (eg, chaplain) to discuss the issue further.³⁰</p> <p>Explore with the patient what or whom would provide meaning for them at this stage of their life.³⁰</p>

Box 2 Continued

<p>3. Considering suicide/ euthanasia</p> <p>"Do you ever find yourself feeling like you are looking forward to death, and wish it would come sooner?" "You've referred several times to wishing it were all over. Can you share with me what you're thinking in that regard?"⁵⁴ "Can you tell me why you wish your life to end?"⁵⁵ "Have you ever thought about or decided how you would end your life?"² "You sound like you have been feeling pretty hopeless... has it ever felt so bad that you'd thought you'd rather be dead? Have you found yourself thinking about taking your own life?"² "Who else knows that you have expressed this wish to end your life?" "Can you tell me about how you've come to this view about dying? Is this something you've thought about today for the first time, or have you been thinking about it for a longer period?" "Have you asked someone to help you or are you planning to do this on your own?" "What views have you had about euthanasia in the past – for yourself, for other people in similar circumstances? Have you ever thought euthanasia should be legal?"</p>	<p>Have end-of-life choices been fully explored with the patient, eg, to identify particular fears or concerns, and to ensure their wishes will be carried out? Ask the patient whether, if the problem could be identified and addressed, they would still be interested in ending their life. "If we could relieve the problem, would you still be interested in ending your life?" Check whether the patient's feelings have changed, eg, "Considering all we have discussed, how do you now feel about ending your life?" Set up some agreements, eg, "Is it ok if we talk about this further?"</p> <p>Is the patient aware of the consequences of their proposed actions for family/friends?</p> <p>Ensure the patient knows exactly about the aims of palliative care, eg, "This is what palliative care aims to do... this is what we can't do..." Consider using the WTHD scale for assessing the intensity and persistence of desire to die.^{12,57}</p> <p>Is the patient competent to make such a decision, ie, is the patient confused or disoriented? Does the patient have a past history of suicidal attempts, psychiatric issues, alcohol/drug abuse or recent significant bereavement?⁵⁸</p> <p>Is the DTDS persistent, eg, several times per day/ or each day for a week? Is the patient aware that legally (where pertinent) you cannot assist? However, does the patient understand that the palliative care team will continue to care? Where appropriate, state clearly what is permissible, eg, "Although by law we cannot legally assist you we will not abandon you. I will do my best to address your concerns, and we can give medications to relieve your pain and suffering."⁵⁴ If the patient is still seeking suicide, euthanasia, physician assisted suicide (if legally allowed in your jurisdiction) refer to relevant guidelines, eg.^{44,59}</p>
<p>4. Seeking health professional assistance with hastened death</p> <p>Initial response should never be merely 'yes' or 'no'.^{44,46,56} Answering 'yes' without exploring the meaning of the request is inappropriate and in most contexts, illegal. Answering 'no' leaves the patient in a situation of helplessness to control his or her destiny and closes off further communication. We should talk a lot more about this. Before we can know what way to proceed, let's talk about why you are asking me to help you die...⁴⁶ "Can you tell me how you've come to feel like this and why you want to take this action?" "Have you been able to discuss your concerns about the future with health professionals who are most involved in your care?"</p>	

Conclusion

It is not uncommon for health professionals to be confronted with a patient's request to hasten their death. Despite this, there is a dearth of literature guiding health professionals on how best to respond. It is clear from our examination of this issue that opportunities are being missed for health professionals to respond in a meaningful way to patients' expressed desire for hastened death. In the context of palliative care, some health professionals may consider that DTDSs belong to a sphere beyond their expertise. Providing health professionals with sound strategies to consider when confronted with a DTDS may encourage them to face the issue with confidence, rather than avoiding it.

The recommendations in this article were developed using a range of expert clinicians and academics reaching consensus and are not intended to be prescriptive. Health professionals should draw on a sound person-centred framework for responding to a DTDS rather than relying on a dogmatic approach that may inhibit dialogue. Open dialogue is fostered within a climate of trust, where patients feel free to discuss their fears and anxieties, as well as their joys and their hopes. In the context of life-threatening illness, an expressed desire for hastened death may be a request to be heard and to be understood. It is essential, therefore, that health professionals receive guidance in discerning the appropriate response.

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