Dignity Group Workshop (tables 1 & 2)

Instructions

Outcome - **Tables 1 & 2 consider Dignity as a concept**

- Table 1 – **Look at the Poem When I am old I shall wear purple** (discuss for 15 minutes)

  Table 2 – **Look at 'Dignity, what does it mean document?** (Discuss for 15 minutes)

The two groups then combine and collaborate to compare notes in order to do a (not longer than) 5-minute presentation at the end on dignity and what it means to you.
This isn't about right or wrong answers in terms of management, much more about the patient's, family's and your attitudes and feelings.

The presentation can involve all or just a few of you – can just be a summary of your discussion or innovative and entertaining. The Aim is to educate the rest of the audience quickly

(If you have time to spare and you will have a total of an hour in total – go back into groups and discuss the other work).

The material is on subsequent pages but don't feel you have to include this, think globally, think about your own families, young and old. Think about your own experiences and stories too.

Table1. Material

When I am Old I Will Wear Purple
Jenny Joseph's 'Famous Poem'
Warning!
When I am Old
I will wear Purple!

When I am an old woman,
I shall wear purple - -
With a red hat which doesn't go,
and doesn't suit me.
And I shall spend my pension
on brandy and summer gloves and satin sandals,
And say we've no money for butter.
I shall sit down on the pavement when I'm tired
and gobble up samples in shops
and press alarm bells
and run with my stick along public railings,
and make up for the sobriety of my youth.

I shall go out in my slippers in the rain
and pick flowers in other people's gardens
and learn to spit!

You can wear terrible shirts and grow more fat
and eat three pounds of sausages at ago,
or only bread and pickles for a week,
and hoard pens and pencils
and beermats and things in boxes.

But now we must have clothes that keep us dry,
and pay our rent
and not swear in the street,
and set a good example for the children.
We must have friends to dinner
and read the papers.
But maybe I ought to practice a little now?
So people who know me
are not too shocked and surprised
when suddenly I am old,
And start to wear purple! (By **Jenny Joseph)**

Table 2 Material

Everybody Matters: Sustaining Dignity in Care

What do we mean by dignity?

Dignity in hospital is widely advocated but it is a concept that has broad and varied meanings and can mean very different to different people. This diversity of meaning means that within the Dignity in Care project, we have adopted a particular framework to understand dignity which is based on the idea that in hospital it is vital not just to think about the patient but that both staff and relatives are important when promoting dignity – **the idea that everybody matters.**

The theoretical aspects of “everybody matters” are based upon the work undertaken by Help the Aged and the University of Sheffield (Davies et al. 1999;Nolan et al. 2006) which showed that most effective dignified care considered the well being of not only patients but also their families and those working with them. The quality of relationships in hospital between staff, patients (in this case older people) and relatives was found to be pivotal when considering dignity in hospital. This has been described as ‘a relationship-centred approach’ to care with evidence that dignity flourishes in ‘enriched’ care environments.

The relationship-centred approach to care indicates that to build environments where dignity flourishes a number of ‘senses’ for staff, patients and relatives need to be satisfied. These senses are illustrated below:

A sense of security

For patients	Skilled and timely attentions to physiological and psychological needs to feel safe and free from harm and pain
For Staff	To feel free from physical threat and rebuke and recognition of the physical and emotional demands of the work
For Family Members	Feel able to discuss with staff any concerns in an open and honest manner without fear it will compromise care

A sense of continuity

For patients	Provision of seamless care from known carers skilled at particular points of transition
For Staff	Good working relationships and teamwork with stable core staff
For Family Members	A consistently high standards of care are provided

A sense of belonging

For patients	Build key relationships and maintain family ties
For Staff	To be part of a coherent team
For Family	To feel a partner in care

A sense of purpose

For patients	To have clear goals and aspirations of care
For Staff	To have a clear and shared therapeutic approach
For Family Members	To feel able to plan and feel fully informed of potential care needs

A sense of achievement

For patients	To meet important goals and feel satisfied with the efforts of self and others
For Staff	To use skills and abilities to the full
For Family Members	To know they have played a full role in ensuring the best care

A sense of significance

For patients	To have clear goals and aspirations of care
For Staff	To have a clear and shared therapeutic approach
For Family Members	To feel able to plan and feel fully informed of potential care needs

When the ‘senses’ are met, then patients are likely to perceive care in a positive light.

From an extensive literature review undertaken by the Care for Older Adult Research Team at City University (Bridges, Flatley, & Meyer 2010) older patients tell us this is what they think makes care dignified:

“Connect with me” (create community)

“See who I am” (maintain identity)

“Include me” (share in decision making).

Our findings from the Dignity in Care Project suggest that these values also shared across other patient groups and by hospital staff and in particular nurses.

A recent publication by the Patients Association (2009) shows that we still have a long way to go in addressing the dignity of patients in hospital. The challenge to build and develop dignity in care for patients in the NHS is pressing. We need to work towards building enriched care environments where the ‘senses’ are satisfied for patients, staff and family members/visitors and positive relationships flourish.

References

Bridges, J., Flatley, M., & Meyer, J. 2010, "Older people's and relatives' experiences in acute care settings: systematic review and synthesis of qualitative studies", *International Journal of Nursing Studies*, vol. 47, no. 1, pp. 89-107.

Davies, S., Nolan, M., Brown, J., & Wilson, F. 1999, *Dignity on the ward: promoting excellence in care. Good practice in acute hospital care for older people.*, Help the Aged, London.

Nolan, M. R., Brown, J., Davies, S., Nolan, J., & Keady, J. 2006, *The Senses Framework: improving care for older people through a relationship-centred approach*, University of Sheffield, Sheffield.

Serious illness Group workshop (tables 3 & 4)

Instructions

Outcome - **Tables 3 & 4 consider what happens when an older person gets a serious illness.**

Table 3 – **Mr Phillips case unexplained weight loss** (discuss for 15 minutes)

Table 4 – **Look at Stroke case histories?** What are you experiences in hospital and primary care? (discuss for 15 minutes)

The two groups then combine and collaborate to compare notes in order to do a (not longer than) 5-minute presentation at the end on how doctors and patients deal with serious illness in the elderly and what it means to you.
This isn't about right or wrong answers in terms of management, much more about the patient's family's and your attitudes and feelings.

The presentation can involve all or just a few of you – can just be a summary of your discussion or innovative and entertaining. The Aim is to educate the res of the audience quickly

(If you have time to spare and you will have a total of an hour in total – go back into groups and discuss the other work).

The material is on subsequent pages but don't feel you have to include this, think globally, think about your own families, young and old. Think about your own experiences and stories too.

Table 3. material

Mr Phillips is 84, he has had a fit and active retired life.
He developed a persistent cough following a presumed URTI some 3 months ago and this is affecting him when he is eating-‘the thing that is really bothering me doctor, is the weight loss-I have lost 7lbs in the past 2 months.’

How would you go about investigating the gentleman?

What if tests were normal?

There is a lot to explore here – not just the obvious medical investigation and treatment, but also the family, the ‘ICE’ and the psychological and social.

Table 4. material

UK and US cases – how typical?

Case study:
Stroke patient's speedy treatment

Brian West, 73, from Pinner, was one of the first patients to be treated in the North West London Trust's new Hyper Acute Stroke Unit at Northwick Park Hospital.

He describes the experience as "miraculous". He collapsed at 2:30am on a Monday, feeling sick and dizzy with weakness in his legs. His wife called an ambulance and he managed, with help, to get downstairs when the paramedics arrived.

'I was taken to A&E and then immediately given a scan,' he says. "Then they gave me these clot-busting drugs to re- move the obstruction that had caused the stroke. About 7am my wife left and by 8am I was offered breakfast.

'I felt fine. By mid afternoon Dr [David] Cohen came round and saw me. He asked how I was and I said I was fine. Then a physiotherapist called and asked if I wanted to try walking, which I did. By the following day I was fit to go home.'

Mr West was not unfamiliar with stroke. He had one three years previously following a triple heart bypass and was in hospital following complications for three and a half months. So the experience this time – in and out of hospital in less than two days – was a revelation for him.

The London stroke project aims to reduce deaths by 500-600 per year, in addition to significantly reducing long-term disability. With eight HASUs and 24 SUs ready to go for the 19th July go-live date across the capital, the intention will be dramatically

Increasing Clients' Longevity and Quality of Life

American CASE HISTORY (compare with the UK)

RECOVERY FROM A STROKE

Mrs. P was an independent, cheerful and busy 74-year-old widow who ignored her high blood pressure for years, until she suffered a stroke that left her paralyzed on the left side and unable to speak clearly. Her only son worked in Japan and couldn't spend more than a week with her following the stroke. After a week in the hospital, Mrs. P was transferred to its rehabilitation unit, where her progress was deemed too slow to meet Medicare criteria and she was rapidly discharged. The hospital social worker arranged for her transfer to one of the few available beds in a lower- to mid-quality nursing home.

Mrs. P's trustee visited her several days later and found her crying in bed. The remains of breakfast and lunch were on her clothing, her bed was saturated with urine and her hair was unkempt. She was in the middle of the three beds in the room; one of her roommates called out continually. The only nurse assigned to the floor was unavailable to speak with the trustee and the Director of Nursing was out of the building.

The trustee contacted a care manager that afternoon about Mrs. P's status, requesting an assessment. That evening, the care manager visited Mrs. P and concluded in an interview that she was mentally alert despite her speech impairment. Mrs. P expressed her desire to leave the nursing home and return home. The care manager had her sign a professional consent for a medical records review, then had the evening supervisor authorize it as well.

From the chart, the interview with Mrs. P, and a conversation with her physician, the care manager determined that a slower paced rehabilitation program was needed. Because of an ongoing working relationship, she arranged for Mrs. P's admittance to a high quality nursing home the next day, and for participation in their excellent rehab program for stroke patients.

The care manager also arranged for a physician who specialized in rehabilitation to manage her program. Mrs. P remained there for six weeks. The care manager visited weekly to observe progress, participate in care conferences, and provide support. She also worked with Mrs. P on home discharge plans.

During this time, the care manager met the trustee at Mrs. P's home to see if it could be made accessible for her. With Mrs. P's and her son's approval, a ramp was built for the back door, the bathroom door was widened, and grab bars were installed in the bathroom. The soft double bed was replaced with an electric twin bed, a tub transfer bench and Swedish shower were installed, a Lifeline emergency call button was ordered, and phones with programmed buttons were installed in the kitchen and bedroom. The cost of all modifications was approximately $2400.

When Mrs. P was discharged after six weeks of speech and occupational therapy, she was walking with a leg brace and quad cane. She could dress herself, use the bathroom alone, and speak adequately in short sentences. She needed help with bathing, laundry, shopping, and significant cooking, but could warm up food in the microwave.

The care manager arranged for a personal care aide three days a week, three hours a day, at about $40 a day. The aide helped her bathe, and did laundry, grocery shopping, and meal preparation under Mrs. P's directions. The trustee arranged to sell the car, and the care manager helped her apply for Metro Mobility.

The trustee's timely intervention, the superb rehab service, her determination, and the care manager's coordination of services facilitated an excellent recovery and return home-a far different outcome from that which would have occurred had Mrs. P. remained in the original nursing home.

Functional assessment: Group workshop (tables 5 & 6)

Instructions

Outcome - **Tables 5 & 6 consider what happens when an older starts to fail – how do you assess their function**

Table 5 – **Mrs Phipps - struggling at home** (discuss for 15 minutes)

Table 6 – **Mrs Ash – struggling to cope** (discuss for 15 minutes)

The two groups then combine and collaborate to compare notes in order to do a (not longer than) 5-minute presentation at the end on how doctors and patients deal with functionally assessing in the elderly and what it means to you.
This isn't about right or wrong answers in terms of management, much more about the patient's family's and your attitudes and feelings.

The presentation can involve all or just a few of you – can just be a summary of your discussion or innovative and entertaining. The Aim is to educate the res of the audience quickly

(If you have time to spare and you will have a total of an hour in total – go back into groups and discuss the other work).

Note - in the case for table 5, you are given the chance to work out what you would do.
In the case for table 6 – you are given some solutions but need to work out how practical this would be in general practice.

The material is on subsequent pages but don't feel you have to include this, think globally, think about your own families, young and old. Think about your own experiences and stories too.

Table 5. material

Mrs Phipps, 88, is brought to the surgery by a concerned neighbour- she is struggling to cope at home.
She has lived alone since the death of her husband 10 years ago and her children live in Australia.
She has osteoarthritis and controlled hypertension and is not a regular attendee.
She fell in the garden a few weeks ago and couldn't get up until her neighbor arrived and helped her. She has seemed a little more vague over the last year and sometimes forgets to bring the milk in.

Where do we start to unravel this?

How would you assess her functionally?

In the case for table 5, you are given the chance to work out what you would do. (is some resource material at the end)

Table 6 . material

Mrs Ash is an 84 year old woman with chronic health problems including cataract, osteoarthritis, and mild cognitive impairment. She has lived on her own since the death of her husband. She has attentive friends, but no formal support. She is brought to your general practice surgery by a concerned neighbour who feels Mrs Ash is “struggling to cope.”

In the case for table 6 – you are given some solutions but need to work out how practical this would be in general practice.

Assessment

You recognise the need for basic functional assessment. Initially Mrs Ash denies any problems. Using the questions in box 3 you ask specifically about basic activities of daily living, falls, continence, memory, and mood. Using these direct but non-threatening questions she admits to problems with dressing and climbing stairs. Her neighbour confirms these problems and adds that Mrs Ash’s eyesight seems to be a problem, that she doesn’t go out as much, and sometimes needs help with the shopping. You have already noticed that Mrs Ash used a table to steady herself when walking from the waiting area to your consulting room—“furniture walking.” Focused physical examination shows general muscle wasting and no focal neurological deficits. You note that she struggles to read large print in a magazine.

You arrange for a longer home visit at the next opportunity. In the home environment you ask Mrs Ash to demonstrate her mobility on stairs, her ability to dress herself, and transfers on and off a chair. You note her antalgic gait, particularly on the stairs; that she uses the arms of the chair to help her get up from it, so she would need a handrail to get up from the toilet (at a similar height); and that her visual problems complicate dressing. You mention that her arthritis must make it difficult to do the shopping and cleaning, and she admits that “sometimes she relies on friends to help but that it would be nice to be able to go out more often.”

Outcome

You create a problem list with important items of: visual impairment affecting reading and dressing; general deconditioning and pain from osteoarthritis impairing chair and toilet transfers and ability to go out on own, shop, and clean; lack of mobility causing some social isolation.

With Mrs Ash’s agreement, arrangements are made for ophthalmic review; analgesia is prescribed; help with shopping, cleaning, and laundry is arranged through social services; and an occupational therapy assessment for toileting aids is requested. You recognise that a more comprehensive assessment of mobility and care needs is required and refer Mrs

Ash for multidisciplinary assessment through the local care of the elderly team.

Patients may omit important symptoms, rationalising them as an inevitable consequence of ageing or fearing that admitting to problems may lead to placement in a care home. While exploring activities of daily living, make the distinction between what the patient wants to do, what they can do, and what they actually do—with the last descriptor being the most important.

With the patient’s consent, proactively seek a history from as many perspectives as possible (family, carers, care home staff) to give a more objective description of current and previous function. Use health records, particularly to confirm extent or rate of decline. This process is easiest if information is available in a structured format such as the ADL questionnaires discussed below.

Resource material – summarized from

Functional assessment in older people

BMJ 2011; 343 doi: http://dx.doi.org/10.1136/bmj.d4681 (Published 22 August 2011)

Summary points

In older adults functional decline is a common presentation of many disease states.
Causes and consequences are diverse, so functional assessment is not suited to a traditional medical model of system based history and examination
Consider functional assessment "screening": where illness has caused change in function; before considering long term care; and when planning major elective procedures in older adults
Validated scales for assessing basic and extended activities of daily living can help inform and focus history taking
Key elements of the physical examination include subjective "end of the bed" assessment; upper and lower limbs; vision; hearing; and the patient's environment. Functional decline is rarely related to a single problem, a problem list can guide intervention. When functional change is evident, referral for multidisciplinary, comprehensive geriatric assessment is often needed
Older people often present to healthcare services with acute and chronic problems that act together to adversely affect function. A common pathway comprises functional decline, followed by loss of independence and need for institutional care. However, this process is not necessarily inevitable or irreversible. Timely recognition of functional difficulties can lead to interventions that may prevent or arrest the decline.

Activities of daily living (ADL): These are "everyday tasks," ranging from aspects of self care that are needed daily (such as toileting and eating—often described as basic or personal ADLs) through to more complex tasks (such as shopping, using a telephone—often described as instrumental or extended ADLs). When a person has difficulty with one or more basic activities, daily support (from family or carer) is needed for the person to remain safe
Comprehensive geriatric assessment: The simultaneous multilevel assessment of various domains by a multidisciplinary team to ensure that problems are identified, quantified, and managed appropriately. This includes assessment of medical, psychiatric, functional, and social domains, followed by a management plan that often includes rehabilitation[1]
Disability: A construct described in the World Health Organization's *International Classification of Functioning, Disability and Health* (ICF).[2] Disability (now termed activity limitation) refers to restrictions in performing usual tasks. ICF terminology recognises two other levels of function: physical impairment and handicap; all these levels of functioning are interconnected.[2] Quality of life measures seek to describe outcomes beyond participation in society and are outside the scope of WHO-ICF
Frailty: A popular conceptual definition of frailty is "the propensity to deteriorate in the face of a stressor."[3] Frailty constructs range from simple measures of physical function, such as grip strength, through defined physical phenotypes, to complex multidimensional indices that are useful in research but difficult to apply in clinical practice
Functional ability: Primarily refers to performance of basic and extended ADL to maintain safety. Thus functional ability is a global term and not synonymous with the more focused label "physical function." Although the focus of this review is physical function, comprehensive functional assessment should also include cognition, mood, and carer related matters

What is an assessment of functional status and why does it matter?

Decline in function itself may be a presentation of otherwise occult pathologies[4] so, not surprisingly, it is associated with increased mortality.[5] Relatively minor insults (such as changes to drugs and constipation) may precipitate substantial deterioration in function.[4] Systematic reviews have shown that intervention based on comprehensive geriatric assessment can improve physical function and reduce admission to care homes and hospital in older people.[1,6,7] The first step in this process is the recognition and description of functional problems—this task should be routine for all health professionals and not the sole preserve of the geriatrician.

It is unusual for patients themselves to identify functional decline,[8] and assessment precipitated by "crisis" remains common.[9] Because functional screening of unselected older populations has not consistently improved clinical outcomes,[10,11] opportunistic assessment is preferred and should form part of consultations for management of chronic diseases. We suggest a process of functional evaluation based on structured history and examination, which may be supplemented with standardised assessment instruments.

- **Feeding:** Are you able to feed yourself? Can you cut up food without help?
- **Bathing:** Are you able to take a bath or shower without help? Are you confident to take a bath or shower with no one in the room or house?
- **Grooming:** Do you need help with brushing hair, shaving, or applying make-up?
- **Dressing:** Can you get dressed without help? Can you manage buttons and laces?
- **Continence:** Do you ever wet yourself if you are not able to get to the toilet in time? Do you ever soil or mess yourself with bowel motions?
- **Toileting:** Do you need help to use the toilet?
- **Transfers:** Are you able to get out of bed and on to a chair with no help?
- **Mobility:** Are you able to walk 50 yards on the flat with no help? Do you use any walking aids such as a stick or frame? Have you fallen or stumbled in the past year?
- **Stairs:** Are you able to climb a flight of stairs without help?
- **Extended or instrumental ADL (based on the Nottingham extended ADL scale)**[17]
- **Mobility:** Are you able to walk outside on uneven surfaces? Are you able to travel on your own to local destinations? Do you feel confident to use public transport?
- **Leisure:** Are you able to continue your previous hobbies? Are you able to stay in contact with friends and family?
- **Domestic:** Are you confident in managing your finances? Are you able to go shopping for essentials? Can you manage your laundry?
- **Kitchen:** Are you able to make a hot drink or snack? Are you able to walk with a hot drink without spilling it?
- *This structured history includes screening questions for continence, mobility, and falls

Standardised assessment tools

Many such tools are available for use in different settings or disease states, but no consensus exists on the optimal measure,[22,23,24] and detailed knowledge of scales is not essential for the general clinician.

However, awareness of some of the more prevalent instruments may help in communicating with other professionals and in interpreting older age research (box 6). Moreover, functional assessment need not involve detailed and time consuming scales. For example, the get up and go test (box 5) is as useful for predicting falls as many more complex tools.[19] If time allows, use of a longer validated assessment instrument can have added value—for example, instrumental ADL tools such as the Nottingham scale[17](box 3) or Lawton scale (box 6)[25] give standardised quantifiable data that may avoid the ceiling effects associated with common assessments of basic activities of daily living.

What are the challenges?

We recognise that functional assessment is not always straightforward. However, with the guidance offered we hope that basic assessment should be feasible in a busy practice. The assessments require some initial investment of time, but the combination of early recognition of functional decline and appropriate referral is ultimately more efficient than the multiple consultations that may result if functional problems are left to progress.

Although history taking is the cornerstone of assessment, it poses particular challenges in many older people. Barriers to communication will be more prevalent and can include cognitive impairment (delirium or dementia, or both), deafness, depression, dysphasia, and distraction caused by pain or emotional distress. General rules include the importance of speaking clearly and not too quickly while facing the patient and giving adequate time to respond. The importance of collateral history has already been emphasised.

Many older people have a complex array of medical comorbidities, functional problems, and difficult social circumstances. In these situations it is easy to feel overwhelmed, but we must avoid therapeutic nihilism. For those who perform poorly on the most basic functional assessment tasks there may still be the opportunity for meaningful improvements. A return to complete independence may not be possible for all, but small gains can greatly improve functioning and quality of life. For example, regaining the ability to move from bed to toilet independently with appropriate equipment may mean the difference between staying at home and requiring institutional care.

Busy general clinicians may feel that functional assessment is not part of their remit. With an ageing population, all clinicians are likely to encounter functional problems in their patients. Although not all clinicians have the training and infrastructural resources to offer a comprehensive assessment or rehabilitation interventions, all clinicians should screen for functional problems in older patients so that referral can be appropriately directed (box 4).[27]

Medico legal problems: Group workshop (tables 7 & 8)

Instructions

Outcome - **Tables 7 & 8 consider what happens when an older person runs into medicolegal issues. What do you do?**

Table 7 – **Mr Jones - relative insists on hospital** (discuss for 15 minutes)

Table 8 – **The demented driver** (discuss for 15 minutes)

The two groups then combine and collaborate to compare notes in order to do a (not longer than) 5-minute presentation at the end on how doctors and patients deal with Medico legal issues in the elderly and what it means to you.
This isn't about right or wrong answers in terms of management, much more about the patient's family's and your attitudes and feelings.

The presentation can involve all or just a few of you – can just be a summary of your discussion or innovative and entertaining. The Aim is to educate the res of the audience quickly

(If you have time to spare and you will have a total of an hour in total – go back into groups and discuss the other cases).

The material is on subsequent pages but don't feel you have to include this, think globally, think about your own families, young and old. Think about your own experiences and stories too.

Table 7. material

You are called to a nursing home to see an elderly man, Mr Jones with a chest infection.

In his care plan, it states he would like to be cared for at the home and that he would not like to be transferred to a hospital should he fall ill.

After reviewing him, you note he has severe pneumonia and is at risk of death. His daughter is present and comments on how confused and breathless he is.

You explain that he needs intravenous antibiotics and oxygen in hospital but unfortunately his care plan states that you have to treat him in the nursing home, which does not have the facilities for oxygen or intravenous drugs.

She objects to this and, despite the care plan, insists he is transferred to hospital.

What are your options?

Some answers below (try not to cheat too soon)

Opinion on table 7 – Mr Jones case

GP's view - Dr Dan Bunstone is a GP principal in Cheshire The three key issues for consideration are the clinical need to treat the patient, the patient's wishes and the current wishes of the family. If the patient has made a previous advanced directive while fully competent to do so, then this would be my primary consideration.

I would like to know how and when the directive was made and if the patient had capacity to make the decision at that time. Did they really mean they wanted to be left to deteriorate with a potentially curable illness, or did they perceive this directive to apply for something more serious such as terminal stroke or cancer care? If we believe the directive was made with full understanding and capacity, then the patient's wishes need to be observed. The daughter will be angry, and will instinctively want to do all that she can to keep her father alive. I would invite the daughter to discuss the situation, and where possible to involve other family members. My aim would be to reach a common decision with which everyone is happy.

If there continues to be conflict and no resolution achieved, we could apply to the court for a decision to be made. This is a tricky and not uncommon problem we encounter. It highlights the problems of advanced directives and the importance of next of kin being involved.

A medico-legal opinion - Dr Pallavi Bradshaw is a medico-legal adviser for Medical Protection Society This scenario is not uncommon and many GPs will find themselves in similar situations. It is important to remember that your primary duty is to your patient.

There are many complex legal and ethical issues related to autonomy, capacity and consent. Case law, statute (Mental Capacity Act 2005 and Adults with Incapacity Act 2000) and GMC guidance are increasingly emphasising a patient's right to determine their treatment.

The patient appears to lack capacity but you should confirm this formally and document your findings. The care plan states the patient's wishes, but it is unclear whether this life-threatening situation was ever contemplated. Further, you should bear in mind how long ago the care plan was made and whether there is any indication that his views may have changed or that he lacked capacity at the time of those discussions.

As you are unsure about these aspects and in the absence of a lasting power of attorney or welfare attorney you should act in the patient's best interests.

You should take into account the clinical aspects, the patient's known views, values and beliefs and indeed the daughter's concerns. If you are uncertain about the clinical assessment you should request a second opinion and ensure you keep detailed records of the decisions taken.

A patient's view - Danny Daniels is an expert patient Personal care plans are packages of care that are personal to the patient.

It involves working with professionals, who understand their needs, to agree goals, the services chosen, and how and where to access them.

There appears to be three main questions that arise:

1. Is the care plan valid and was it arrived at using a designated code of practice and co-signed and witnessed?
2. During the process of completing the plan, were the implications of possible refusal of hospital treatment in the future explored in depth?
3. Does the patient's present capacity to understand override his previously expressed wishes?

The GMC guidelines are comprehensive and give valuable indicators on what actions the clinician should do in such circumstances. Their online guidance sections 75-79 are particularly helpful.

The Mental Capacity Act 2005 section 4 is also an applicable reference, particularly in terms of the patient's capacity to understand in his present condition.

On one hand we have the daughter who would like to see her father's health improve. And, on the other, we have the clinician following the wishes which were previously expressed when the patient was cognisant.

This is a difficult situation for the GP to be in.

Table 8 . material

The Dilemma - You have been the GP to an elderly couple for over 20 years. The wife is disabled by arthritis and the husband has been slowly developing dementia. They never ask for a home visit as he always drives her to the surgery. While giving them the annual flu jab, you realise that his dementia has progressed and he no longer knows your name. As they go to leave the room you realise he is still driving. There is no record of anyone telling him to inform the DVLA.

What will you do?

A GP's view - Dr Barney Tinsley is a GP partner in Yorkshire

Driving ability is very difficult to assess in patients with any degree of memory impairment or dementia. The guidance from the DVLA states that 'Those who have poor short-term memory, disorientation, lack of insight and judgment are almost certainly not fit to drive.'

Firstly, don't let them leave the consultation just yet. It would appear that the husband has not had a formal assessment of the severity of his dementia, although the snapshot of his condition during this consultation shows that his short-term memory might be significantly impaired. It is difficult to make a potentially life-changing judgment based on this alone.

The GP could perform a mini-mental state examination or abbreviated mental test score on the patient. Anecdotal information regarding his memory and day-to-day activity from his wife would also be of use.

It may be useful to take advice from the on-call elderly medicine registrar regarding the patient's driving, which the GP could relay to both the husband and wife during this consultation.

Common sense might dictate that we would strongly recommend he should not drive from then on, until further assessment is performed, and the husband should be given the chance to stop driving voluntarily from that point. This is unrealistic, especially as they need to get home from the surgery.

If the patient does lack insight and short-term memory, he is unlikely to usefully retain this information; a home visit or phone call later in the week to the patient's wife to ask whether he remembers the conversation, or to check whether he has continued to drive is in the best interests of the patient and other members of the community.

The DVLA has a team of experienced medical advisers who can be consulted via telephone to help with the advisory process; it may be that this patient needs its formal intervention with deciding whether he is fit to drive, which would most likely be after he is formally assessed via secondary care. If this patient does continue to drive, it is ultimately the GP's duty to inform the DVLA about this.

In addition to this driving dilemma, is the issue of this couple's continuing ability to cope in their own home, should they be unable to continue using a car. With the couple's agreement, referral to the community matron and/or social services might be useful to explore home care, meals on wheels, access buses, day centres and occupational therapy assessment for the home.

A medico-legal opinion - Dr Angelique Mastihi is a medico-legal adviser at the MPS

The transport secretary acting through the medical advisers at the Drivers Medical Group, DVLA, has the responsibility to ensure that all licence holders are fit to drive.

The regulations apply to all drivers and they have a legal obligation to inform the DVLA if they suffer from one of a specified list of conditions, which may affect their ability to drive. If a doctor suspects that his patient has not informed the DVLA of a medical condition he must inform the patient of their legal duty to do so.

In this case there is no record of the doctor advising his patient to contact the DVLA at an earlier stage of his dementia. What is now paramount is that the doctor advises the patient that he should no longer drive. It appears possible that the gentleman is now no longer in a position to advise the DVLA himself.

Therefore the doctor should inform the patient that he will take steps to notify the DVLA. This conversation should be documented in the record and a letter sent to the patient confirming the action taken.

It may be that the patient is no longer in a position to consent to the disclosure of this information to the DVLA. However, in line with the recent GMC guidance 'Confidentiality', the information can be disclosed in the public interest in order to protect both the patient and public from serious harm. It would also be good practice to involve the patient's wife.

A patient's view - Elizabeth Brain is a member of the RCGP patient partnership group

Firstly, you must inform the husband of what he is legally obliged to do and secondly, for your own integrity, you should record that you have done so. Clearly, a probable cessation of driving will have a major impact on their family life, but the absence of surgery visits can be mitigated by home visits.

It is a legal requirement for a dementia sufferer to advise the DVLA as soon as dementia is diagnosed. In return, it will write to the person and seek their permission to contact their GP and discuss the extent of their condition.

Depending on the information received, the DVLA may allow him to continue to drive or may ask for a driving assessment. The patient, if able, should also advise his insurance company as his policy may become invalid.

The absence of any record of the above advice is unfortunate but does not preclude a record being entered once the advice has been given.

End of life problems: Group workshop (tables 9 & 10)

Instructions

Outcome - **Tables 9 & 10 consider what happens when with end of life issues in the elderly. What do you do?**

Table 9 – **Margaret with no relatives** (discuss for 15 minutes)

Table 10 – **Consider the Question – Why aren't we allowed to die naturally anymore?**(discuss for 15 minutes)

The two groups then combine and collaborate to compare notes in order to do a (not longer than) 5-minute presentation at the end on how doctors and patients deal with <u>end of life issues in the elderly</u> and what it means to you.
This isn't about right or wrong answers in terms of management, much more about the patient's family's and your attitudes and feelings.

The presentation can involve all or just a few of you – can just be a summary of your discussion or innovative and entertaining. The Aim is to educate the res of the audience quickly

(If you have time to spare and you will have a total of an hour in total – go back into groups and discuss the other cases).

The material is on subsequent pages but don't feel you have to include this, think globally, think about your own families, young and old. Think about your own experiences and stories too.

Table 9. material

Margaret is a 92-year-old widow with no children and no surviving relatives. She was a music teacher and a very accomplished pianist. She lives alone, but is becoming increasingly frail and experiencing progressive short-term memory loss. She manages to remain in her home only through the intensive support of a number of good friends. She has made a will, has a prepaid funeral plan and appointed a friend some years ago with enduring power of attorney (EPA).

Her GP has asked her if she would like to make an advance statement of wishes, but she has declined, preferring not to talk about it and saying: 'I am sure you will do the best for me when the time comes.'

If her dementia becomes advanced and decisions have to be made about her treatment or place of residence what will you do to manage her condition?

How will you manage decisions regarding resuscitation if she deteriorates at home?

How would your decision differ should she be in a nursing or residential home?

(Note: it may be necessary to appoint an independent mental capacity advocate, because her EPA does not have authority to make such decisions. If Margaret needs to move to residential care, this would be a good opportunity to try to establish a formal plan for her care, while she still has the capacity to do so.)

Table 10. material

Consider the Question – Why aren’t we allowed to die naturally anymore?

You might find the material below of interest.

Memento Mori: Iona Heath – Past president of RCGP 2012

How is it that at the beginning of the 21st century, we have forgotten how to die and have even forgotten that death is itself a gift? The art and literature of previous generations was steeped in the tradition of *memento mori* designed to make humanity explicitly aware of the brevity of life and of the urgent need to use the short time to its limits. Today, we who live in the richer countries of the world have the unprecedented good fortune of a gratifyingly extended expectation of life but, apparently still dissatisfied with this, we seem to want to push it further and pretend that life can be indefinitely extended. Public rhetoric now attaches more value to the length of life than to its intensity—and the whole of health and social policy seems to be predicated on the belief that everyone wants to live forever. There is no allowance in this view for those whose lives are full of doubt and desperation and a recurring uncertainty as to whether life is worth living at all; no room whatsoever for an understanding of suicide. And yet, as Primo Levi reminded his readers, the gift of death is that while it places finite limits on the possibility of infinite happiness, at the same time and in precisely the same way, it curtails the possibility of infinite suffering and infinite despair.

Today, of course, we remain aware of death but in an unacknowledged, almost furtive way, and as an undercurrent of fear. It has become an imperative of social responsibility to minimize exposure to risk and the enthusiasm with which we do this insidiously undermines our enjoyment of the excitement and thrill of living. A whole generation of children has been deprived of the delights of playing outside without adult supervision because of a distorted perception of risk. This cosseting of children in the richer countries contrasts all too starkly with the experience of children who have the simple misfortune to be born on the losing side of the equation.

The denial of death within contemporary Western society means that everyone is obliged to stay alive and to struggle for life to the limits of endurance. Patients and relatives ask for more and more treatment and this general expectation makes it very difficult for an individual to choose the different path of letting nature take its course during a final illness. For reasons that are not entirely clear to me, religion too often allies itself with medical science to deny nature. In Italy, this found extreme expression in the case of Eluana Englaro. This 38 year old spent almost half her life in a persistent vegetative state, kept alive by medical technology after a tragic accident in 1992. Her father struggled through every layer of the Italian courts seeking permission to have artificial feeding stopped so that she could be allowed to die. Eventually, in 2008, permission was granted but within weeks and at the last moment, the Vatican questioned the morality of the decision and caused a further delay. Finally, on 9 February 2009, Eluana died, 4 days after her feeding tubes had been removed, and yet the political, judicial and religious wrangling has continued.

In a similar way, but with people who are mostly of a very different age, it has become standard to use feeding tubes when those who have suffered severe strokes or dementia are no longer able to swallow. All this achieves is to close off one of the routes that nature has provided to allow the body to die. Someone suffering from advanced dementia could be said to be meant to develop swallowing problems which lead to pneumonia and so to the escape of death. Nature provides its own exit strategies. So why are we so unwilling to allow nature to take its course; why do we expect doctors to push the boundaries so far in this direction?

Life can be wonderful and the giving and receiving of love, one of its greatest joys; the losing of life or love is terrible and justly feared. Yet, the finitude and the fragility of both life and love are essential constituents of the wonder and the joy.

There seems an urgent need to rediscover traditions of resignation, stoicism and courage in the face of death on the part of both the dying and those who love and care for them. We need better ways of coping with the pain that comes with the loss of life and love. We have allowed long traditions of ritual to wither away but, at the same time, we have lost the framework of behaviour that ritual provided and the comfort and security that this can bring. People feel adrift and uncertain and have little idea what is expected of them. Fewer and fewer people have witnessed others dying. Priests have lost their role and doctors who were the other traditional familiars of death are too busy trying to keep the dying alive.

Yet, in the care of all patients, science takes a doctor a long way but not far enough—and when a doctor looks after a patient who is dying, science becomes even more inadequate. Death occurs at the limits of medicine and doctors have consistent trouble in acknowledging or even recognizing these limits. As a direct result, quite unintentionally but much too often, medicine is used, within contemporary society, to torture the dying. Scott Murray *et al.* interviewed dying patients in both Kenya and Scotland. The Kenyan patients described wanting to die because the pain and the other symptoms of their disease were so awful; patients in Scotland described wanting to die because the side effects of their medical treatment were unbearable. In the United States, a study of the care of patients with either disseminated cancer or advanced dementia, dying in an acute hospital, showed that, for nearly a quarter of both groups, cardiopulmonary resuscitation was attempted and more than half of those with advanced dementia died with a feeding tube in place. Where does this sort of care leave dignity and the possibility of peace? It seems to me to amount to a terrible indictment of the role of medicine in the care of the dying.

In my more than 30 years as a family doctor, I have tried to make sense of this situation by seeking both solace and inspiration in literature. The task of finding meaning in the finite limits of life and in its inevitable losses is common to all humanity and neither the specialist knowledge of doctors nor even their familiarity with death gives them any particular aptitude for this most fundamental of existential tasks. And all of this is perhaps even more difficult for younger doctors who mostly have fewer reasons or opportunities to contemplate their own mortality. Further, with the power of modern medicine, it is all too easy for doctors of all ages to sidestep these issues by giving more treatments and more drugs while avoiding the gaze of the dying person. The effect is to treat the dying person almost as an object in need of a technical fix and this consigns the dying to death rather than to life and treats the dying person as if they were already dead. It is infinitely more difficult for the doctor to remain fully present for the dying person and so to acknowledge the importance of the relationship between two mortal human subjects facing the same existential challenges, albeit across a different timescale.

Writers and perhaps particularly poets face these issues both more obliquely and more directly. The key is that they use words with care, thought and deliberation to approach a truth which is recognized by others with an immediacy that makes them feel less alone because aspects of their experience of life and the world have been acknowledged and described. The greatest poets reveal truths that we, as readers, already know but with a new clarity and a new depth that enriches and extends our experience. As the Nobel Laureate Seamus Heaney wrote 'The world is different after it has been read by a Shakespeare or an Emily Dickinson or a Samuel Beckett because it has been augmented by their reading of it.'

If we are to have any hope of forging a more humane contract between science and nature in the care of the dying, we will need all the help we can get from all the different dimensions of human wisdom that are explored within literature and the other humanist disciplines—and perhaps particularly within poetry.

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AND ("Allow natural death")—could it make a difference?

PERSONAL VIEW **Rachel McCoubrie**

Throughout our medical careers most of us will be involved in DNAR ("Do not attempt resuscitation") discussions with patients and their families. Last year I found myself, for the first time, on the other side of the discussion. My father had longstanding polycythaemia, which transformed into myelofibrosis. In the last month of his life he was admitted to hospital with epistaxis then again, a week later, with deep vein thrombosis and pulmonary embolus. His physician, faced with the dilemma of how to manage a patient with low platelets, proved thromboses, and daily nose bleeds, decided, in discussion with my father and us, on treatment with low dose, low molecular weight heparin.

Two weeks later he was admitted with a massive retroperitoneal bleed. He was not fit for surgery, and admission to a high dependency unit was judged to be inappropriate. He was managed with blood and platelet transfusions, fresh frozen plasma, and Gelofusine to try to normalise his blood pressure. However, he remained hypotensive and became anuric, and his oxygen saturations dropped as he became progressively more fluid overloaded.

It was at that point that the registrar discussed DNAR with my mother, my non-medical sister, and me. She started well, explaining past events and the current problem of not being able to maintain his blood pressure, then asked my mother what she wanted them to do about resuscitation. My mother was clear: she would want him to be resuscitated. She was told that it would be a medical decision, so she asked why she had been consulted in the first place if she had no choice. My sister felt that he should be given "every chance" and asked what difference DNAR would make. I explained that the difference would be that we would be able to sit with him and hold his hand as he was dying, rather than having to leave the room while the team carried out chest compressions to try to restart his heart and breathing. Eventually we all agreed that he should not be resuscitated.

We would not offer a surgical procedure or drug treatment to a patient if we did not expect it to work. The same applies to CPR

The wording of the statement "Do not resuscitate" is in itself negative. To patients and their relatives it can sound as though we are denying patients something that rightfully should be theirs. Doctors, whether junior or senior, sometimes struggle with DNAR decisions. The 2007 revised guidelines from the BMA, the Royal College of Nursing, and the UK Resuscitation Council helped to clarify some of the problem areas, but many doctors still lack confidence in handling DNAR discussions, remain uncertain as to exactly who should make the decision, and are uncomfortable signing a DNAR form.

Many think that the patient has the ultimate choice. This may indeed be the case if there is a chance of cardiopulmonary resuscitation (CPR) working. However, the guidelines are clear that if the medical team judges that CPR would not be successful then it should not be considered, and DNAR can be documented without explicit discussion with the patient. This is because a futile treatment should not be offered. We would not offer a surgical procedure or drug treatment to a patient if we did not expect it to work. The same applies to CPR. Moreover, in weighing up the potential benefits and harms, it might be thought that attempting CPR in the final stages of an incurable illness is subjecting patients to an undignified death.

Some still believe that relatives have a choice. They do not, and they should never be put in the difficult situation of being asked to decide on resuscitation of their loved one. That is not to say that we should not be talking to the family; but our aim should be to discover what the incompetent patient's wishes would have been, not what the family wishes us to do.

If the medical team believes that a patient is dying, it is crucial that the patient and their family are aware of this, so that the patient can have a chance to put their affairs in order and that their wishes concerning place of care and place of death can be ascertained. DNAR will be implicit in discussions about changing the focus of care from active treatment to comfort care and palliation of symptoms. Equally, when planning a patient's discharge home or to a hospice or nursing home to die, the medical team does not need to raise DNAR as a separate issue.

If we do not attempt CPR when a patient's heart and breathing have stopped, we are simply allowing the patient to die naturally without medical interference. CPR was never intended for patients dying at the end stage of an incurable illness. If broaching the topic of DNAR is difficult for doctors, and upsetting for patients and their families, is it time for a major change? Why not change the way we handle this important and difficult issue by, as the ethicist Daniel Sokol argued in a recent *BMJ* column (*BMJ* 2009;338:b1723), simply changing the terminology to the more positive, and perhaps more comforting, "Allow a natural death"?

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Cultural differences in old age: Group Workshop (tables 11 & 12)

Instructions

Outcome - **Tables 11 & 12 Cultural differences in the elderly**

- Tables 11 and 12 please combine to look at cultural differences in the elderly. (Discuss for 15 minutes)

The two groups will ultimately collaborate to compare notes in order to do a (not longer than) 5-minute presentation at the end on <u>cultural differences in the elderly</u>

This isn't about right or wrong answers in terms of management, much more about the patient's, family's and your attitudes and feelings.

The presentation can involve all or just a few of you – can just be a summary of your discussion or innovative and entertaining. The Aim is to educate the rest of the audience quickly

(If you have time to spare and you will have a total of an hour in total – go back into groups and discuss the other work).

Plan

Combine the two tables into one large group then re-divide into small subgroups.

Rather than mix you up into small groups we want to try the complete opposite.

So could folk get together in up to 5 small groups which you organize yourselves. We want you to **group with people most like you; i.e. similar heritages, cultures, religions.**

If any one of these sub groups is overly large can you split them into smaller groups.

Then in these small groups for 15 minutes
Consider how your heritages, cultures, religions ….

1. **Look after the elderly in life (support for close or distant families / relations, family values etc)**

2. **Look after the elderly after death. It might be the funeral arrangements of your deceased relative or how you look after your surviving relative after the death of their husband / wife / partner etc.**

Finally
Get back into 1 large group and discuss your similarities and differences with regard to the elderly and design a five minute presentation that you will give to the whole audience.