

# The basic elements of end of life care

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## Slide 1

Looking after people at the end of life is something that many people feel quite uncomfortable with.

Death is not part of most of our experience nowadays and also it is a subject which of itself makes us uncomfortable, there is a lot that is unknown about it.

And as with everything else in life, once you understand what is going on and what you're doing, then it becomes much less scary and then it is possible to play a useful role in caring for people at the end of life.

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'Dying is not a medical event, it is a human event'

I think the most important thing to remember, and this is something that I will emphasise right the way through, is that dying is not a medical event but a human event.

There are two key moments in our life – one is when we are born and the other is when we die. Dying defines us in the same way that being born does but also dying is a key moment in a family's life – the death of a loved one is something that will mark that family forever.

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And so it is really important that we remember this at all times. So what is it that makes dying so often medicalised then? I think there are a number of reasons for this.

I think one reason is fear. Sometimes we distance ourselves from what is happening by putting it into a structure, keeping it at arm's length.

I think another reason is sometimes is a bit of drift, things have been medicalised until then and nobody says actually we need to change gear here. We need to stop doing things that are no longer useful and we need to concentrate on what really matters and only on that now. And that often doesn't happen and so people often end up having treatments that they don't need, going through things that they don't benefit from.

But of course sometimes it is really important for dying to be medicalised, there are situations where a person who is dying needs quite complex medical treatment right to the end.

And so the question then is how do we preserve something human when in that situation.

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So how do we keep dying personal? I think that is the question that I am going to try to tackle today.

There are some things that we can do to help people's death to be more personal. One thing is to have people make changes about where they want to be, about how

they want it to be, about whether they want things to stop things or whether they want them to go on.

I think providing privacy is very important to be with one's family, but also solitude can be important at that stage, so being able to provide that at that moment can be vital. I think another thing about helping to de-medicalise dying is that we do our best to foster and sustain the important relationships that the patient has, this is a vital time for relationships, it is a time that will mark those relationships for ever, therefore it is really important that we support those relationships to develop at the end.

Finally I think it is really really important for both the patient and the family that we try to preserve the dignity of the person who is dying, at all times. I think that if we do these things, that whatever the situation that the dying person is in, dying will feel more personal and less medical.

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And so even when the environment is highly medicalised, one can still achieve these qualities. I think that the point is that little things can count a lot in this situation. Little gestures can get through even when one is surrounded by, in fact even more when one is surrounded by, equipment or there are a lot of interventions going on.

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And so the point to remember is that most of the time we de-medicalise, we we make it more personal by intervening less, by stopping a lot of things. However, there are situations where it's equally important that when we de-medicalise by intervening, by doing more. Let me give you an example. I once looked after a young woman who was dying with bowel obstruction from her cancer. And she was being sick, violently sick, probably 15 to 20 times a day. And I can just started working at this hospice, and this woman ended up with two syringe drivers to give her her medication, with a tube down her nose, and a drip.

And I met with the nurses one day and I said to them 'Do you think we have medicalised this too much with all these pumps and tubes and so on?' And one nurse said something I've never forgotten. She said, 'I think you have done the opposite. Until then, her situation was very medical, she was vomiting a lot, she was in pain a lot. Now she's no longer being sick, she's able to hold her children, she's able to be with her family, and the situation has changed completely.'

So sometimes intervention can help de-medicalise a situation and make it more human. But most of the time of course what we're after is to reduce intervention as time goes by, if at all possible.

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So let's start to look at these things one by one. So we've said that people need to choose their own style of dying wherever possible. So that is that is what we talk about when we talk about advance care planning. People need to think about how far they want their treatment to go, when they want to stop, maybe where they want to be, who they want to be with them, maybe who can take decisions for them when they become too unwell, those kind of things. Now for people to be able to plan in advance they need information, so one needs to be open and explain to people about the situation that they are in. We are often nervous about talking openly with people about their illness and their future, but actually that openness reduces fear. People who are not open about what's going on often fear what is hidden. It is always worse to think about something you don't know than something you do, because your imagination can take you to all sorts of places.

If you're open with people you can provide clear information, so that they can get their head round what's going on, but you also provide a plan. You can say "This is what we do if this happens"; or "This is what we do if that situation arises", and that allows you to give them a sense of security. So openness produces security, and people need information in order to plan.

Clearly some people will not want that information and that is their right, but what we need to do is develop a sense where we're listening to what people are expressing, because people will often want information but not seek it very directly.

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The second thing is, as we've said, that it's important to foster relationships. So communication with families is very important too. We've talked a little about communicating with patients, but communication with families is equally important.

Clearly we need the consent of the patient if we are to share information about the patient, but I think what we want to avoid is the kind of situation where the patient knows what's going on, the relatives know what's going on, but they're both afraid of sharing the information together, they're both afraid of upsetting the other, they don't know what the other one knows.

And this is not an uncommon situation in palliative care: what we find is that then when you get people to share information, when both have shared knowledge, when both know the same things, suddenly they start to talk. And suddenly they get a lot closer, and that time is very precious, the closeness is immensely precious for people.

I think the other thing to remember, when we are talking about families, or talking with families, is that what we're talking about is the story of the person who is ill, the person who is dying. But they also have a story of their own; their own lives are going to change and sometimes change very drastically as a result of what is happening. So we need to constantly keep these two perspectives in our view when we're talking to relatives.

And finally, the relatives need information so that they can prepare themselves and plan. Again, information is useful. It allows you to be concrete in what you are thinking, and that in itself can take away a lot of fear.

Information is kind of the key, really to feeling like you've got your feet on the ground. It doesn't take away uncertainty or fear, but it certainly reduces that feeling quite distinctly.

The last thing I wanted to say about communication with families is not to forget children. If there are children in the family, they need to be kept in the loop. And the best people to do that of course are the parents. And so, when we are communicating with families, we should always ask about children, about what they have been told, and support the parents in communicating with them.

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It's also important for relatives to be able to care for their loved one this stage more than ever, and so it's about giving them chances to be with the person who is in sometimes relatives will play a big part in giving physical care to a relative, others will find it quite challenging. Privacy as well have said and also preparing memories so that when their loved one has died, they have got something they can go back to that kind of keeps that person alive, because that is very, very precious, so to give them the opportunities to do these things is vital.

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So that's the background, the preparatory work. But then we're getting to the point where that person is getting very ill and is starting to die. So how do we tell if someone is dying? Well, there are a number of changes.

The person who is going to die becomes bedridden, they become profoundly weak, they're drowsy, they cannot concentrate for a long time, they eat less and drink less, they can only take sips of fluid eventually, they struggle to take their tablets, eventually they spend all their time asleep until eventually they slip into a coma. So there's a kind of constellation of signs which all point to the same direction and with a little bit of experience certainly one can see.

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When it comes to the actual death itself there are a number of changes that people go through. As most people are unconscious when they die, so they go through a number of changes in their conscious level.

At first they're fully responsive, they're participating in what goes on, but as their brain starts to shut down, they become less responsive, they might only their eyes open when you call them, and then only briefly, and then go back to sleep.

Eventually they might only respond if they're moved, for example. Eventually they will not show response to any stimulus at all.

When they show no response at all to any stimulus, we look at three things, we look at:

- Whether they open their eyes
- Whether they breathe regularly
- And whether they move spontaneously.

If when they don't do any of these three things to any stimulus, then they are in a coma.

At the same time in parallel to this there are a number of changes in the. People often go through a phase of what's called Cheyne-Stokes breathing, where are small interruptions every few breaths, say they take three or four deep breaths then they stop for a little bit, then three or four deep breaths, and stop for a little bit.

As time goes by these gaps become longer, and sometimes these gaps become so long that you wonder if they've stopped breathing and they've died although it rarely goes on for long.

I like to warn families about this beforehand otherwise they get very worried when someone goes through a period of apnoea, when they're stopping breathing, but eventually what happens is the reverse happens, the gaps between the breathing become shorter and shorter unless they disappear completely and the person who is dying breathes regularly again like they did originally. But by now they would be deeply unconscious.

And then at the very end, everything becomes totally irregular for a very few minute and then they stop breathing altogether.

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So in order to prepare for somebody dying, the first thing we need to do is to stop doing anything unnecessary, and that means, stopping almost all their drugs. The only drugs they need on now are those that are keeping them comfortable at the time. Nothing else matters. And again – blood tests, and for most people, although not for everyone, giving them intravenous fluids or nutrition – none of these things are helping

them get better or feel better, they should be stopped. At this point, it is really important to be explaining to the relatives what is happening and why.

## Slide 13

When somebody's dying, comfort becomes what matters most of all. We often hold back on medication because we're worried it might make someone more drowsy, or it might give them a side-effect. At this point of course, these things become more secondary because if someone is very uncomfortable, we will need to give them enough medication to keep them comfortable, and to repeat that medication until we get them to that point.

Most of the time, if you give someone an injection, it usually takes about half an hour before you can be sure whether that medication has worked or not. But depending on the medication, especially someone is very distressed then you should repeat as soon as half an hour later, until you get them comfortable, but it does depend very much on the medication itself.

## Slide 14

When somebody's getting to the end of their life, we write them up for injectable anticipatory medicine. We think: what are the common problems people go through? They are pain, confusion, sometimes people can become agitated and restless. And then there's something called the death rattle where the breathing becomes quite bubbly. I don't like the term 'death rattle' but it's a term that's commonly used. It's probably the quickest way to refer to it that people understand. So you need to prescribe medication for each of these situations.

## Slide 15

The fact that somebody's dying doesn't mean that the previous pain that they had will go away. For most of them the pain will continue and so it's important to continue the painkillers they had previously. Another reason to continue painkillers is that if you suddenly stop their painkillers, people can sometimes go into withdrawal which can be extremely uncomfortable as well as dangerous.

As people go unconscious or become weaker, they tend not to shift position in bed and in itself can become very painful. You can try when you're asleep and in bed and you want to turn over, try to stay in the same position. And you find that if you stay in the same position, after a few minutes, you start to ache all over. And that's what happens to people who are not able to turn over in bed. So that pain can become quite intense and it needs treating, and also things like pressure sores and contracture can be painful.

So we tend to prescribe small doses of opioids such as morphine, oxycodone, when it's required, on a PRN basis, and well as looking at changing positioning, changing the position of people every so often, and so on.

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When people are going unconscious, they often go through a phase that we call 'terminal restlessness'. This usually happens just before they go unconscious, maybe the day before they go unconscious they often have a day when they are agitated and restless. It doesn't happen with everybody but it is fairly common.

I'm not sure anyone knows exactly why it happens, I always think people are trying to hold onto things and they can't manage it anymore and that is what makes them restless, but I don't know anyone really knows why. When you have a patient in that situation, you need to make sure there's no underlying discomfort, that they don't have a full bladder that maybe needs catheterisation; that they don't have pain that nobody's treated etc. The other thing is sometimes people get what we call myoclonus, jerky movements in their muscles. And if you look at them superficially you might think this is terminal restlessness. But that can be due to kidney failure, it can be due to opioid overdoses, it can be due to a few other things, but it usually quite distinctive from terminal restlessness. You get a sudden jerk from a group of muscles, then another, then another, whereas restlessness is more like an agitated state.

A good drug for this would be midazolam, small doses of midazolam. Midazolam is a benzodiazepine, like lorazepam or diazepam but it's very short-acting, it works very quickly, and it wears off after about an hour after a couple of hours. Small doses of midazolam repeatedly will often keep people comfortable and settled.

## Slide 17

And then there's this death rattle, this kind of bubbly noise that people make, as they're breathing as they go unconscious. It happens because they cannot swallow their secretions, the phlegm that their chest is producing collects in the throat, we're usually swallowing phlegm all the time, which is why we swallow every few seconds subconsciously. When we're not swallowing effectively, that phlegm collects in our throat, and similarly with saliva that we are producing. That gives this bubbly sound to breathing, which most people recognise. Most patients seem to be unaware of this death rattle and the sound that they are making when they breathe but it can be very hard for relatives to listen to. There are medications such as glycopyrronium or hyoscine butylbromide buscopan which we can use, they are anti cholinergic drugs

And you can give them by subcutaneous injection or syringe driver so that they get a constant injection over 24 hours. The other thing that can really help is positioning. Positioning someone more upright can reduce the death rattle, sometimes, you may want to put someone in a left lateral position so that their mouth can drain. Suctioning looks like a good idea, but it rarely is, unless somebody has really large amount of phlegm in their mouth or they're getting an obstruction with their breathing. Suctioning is rarely useful and often just provokes more secretions.

## Slide 18

Finally when somebody dies. Well, when somebody dies clearly the death needs to be confirmed, there are protocols about how to confirm a death, about who can do it particularly, it's important once this happens that one informs the family as soon as possible.

It is also important to know what to do after somebody has died. So the death has to be confirmed according to local practice, whether it needs to be one of the nurses or doctors who needs to confirm that death has occurred, and then one needs to inform the family as soon as possible and one must not forget to inform the GP as well.

The death certificate needs to be completed and explained to the family.

Remember that people at this stage may be in shock and they can behave in sometimes bizarre or odd ways. You may tell them a lot of things and they may remember very little of it so it's useful to give them written information as well so that they can refer to it too.

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Now that's what happens in the standard situation, but there are some situations that I think I would like to talk about a bit more because you may encounter these. Sometimes you have a patient who cannot hear you well, sometimes it's because they have hearing problems of their own and sometimes it's because there's a lot of noise. They might be ventilated and the noise of the ventilation and the mask that they have on and so on might make it difficult to speak with each other. So what do you do in terms of communication? It's very important to keep it as brief as possible. There's no point in talking to someone at great length who can only understand a little of what you tell them. But do ask about the important things, so for example ask if they are in pain, are they breathless, ask them if they've got any tightness of the chest, ask them how their mouth feels, because mouths often feel dry, especially if they are on ventilation.

Another thing that's useful is to communicate less verbally but more with the physical things you do. So

you would anyway, so offer them a drink, if possible do mouth care or reposition, do things that help you to do something physical to that patient, so that you communicate in order way when you cannot communicate so much verbally.

Some people can use pen and paper, and it would be good to provide this because then they can communicate with you and you might be able to communicate back with them sometimes in that way.

And if it's possible go back to these people more than you normally would, because they are more isolated. That might not be possible, as you might be too busy or they themselves might need to be isolated because they've got something that's infectious.

But I think the essential thing to remember is that little things count for a lot. Those little gestures that we do to someone which to us might not seem much but can make a very big difference to them when they're feeling alone and cut off.

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The second situation that you might encounter is when you have somebody who is at the end of their lives and the relative cannot be present. So what can you do in a situation like that? Clearly if at all possible, it's important to talk to them every day by phone. Have a pre-arranged time if you can, so they don't hang around all day waiting. Of course every phone call when that is happening will make them wonder if something's happened, so if you phone, I always introduce myself and then say "I'm phoning for blah-blah hospital and just want to say nothing has happened but you know, it's good to catch up". You then talk through what's been happening since the last time you phoned and any progress, any deterioration or any risk. Even if things are stable it's important not to give people a false sense of reassurance. It's important to help people to be realistic, even though it's painful. Be empathetic with people, listen to their feelings, you know, it's very easy to understand where somebody is coming from in a situation like this. And it's very tempting to try to reassure them that everything's going to be OK but we don't know that. And it's important not to give false reassurance. But do try to listen their concerns and ask them if there's anything specific as well that they want you to do for the patient, or if there are particular concerns, rather than just the general upset of not being able to visit.

You know, people might say "My father is not able to tell people when he's in pain", for example, and so on. You know, if you listen to particular concerns like that, you know, I think it's really important to do that and to make note of those things and pass them on.

And the other thing is, I always think it's really nice to talk to the patient about their relatives and to say that

you've talked to them yesterday on the phone, of this afternoon on the phone, and to tell them about it when you phone them back, so you give them some kind of sense of connection.

## Slide 21

As I said it's important not to be falsely reassuring or to be unrealistic, so saying something like "We hope he will pick up, but if he continues to deteriorate, he could change quickly, even over a few hours", and also, as I said, to try and make the connection between the patient and the relatives indirectly, to be the messenger and to say "I told him I was phoning you to tell you how he is". Say "Is there anything you would like to tell him?" because then at least you're acting like a sort of proxy. As a kind of messenger.

## Slide 22

Sometimes of course talking to people who cannot visit in particular, people can be really upset. I think in a situation like this you need to help people to feel safer because they're feeling very unsafe. You're not going to make them feel very safe whatever you do but there are things you can do that will help to feel grounded.

I think the first thing is to try and explain the situation briefly: explain the facts. I think once you've done that, don't go into a lot detail; they're not going to be able to take in a lot of details, so just stick to the essentials. I think once you've done that, you kind of empathise with their emotions, you listen to how they're feeling, you ask about how they're feeling, about how this is affecting them. I think it's important because you're not going to be able to do very much over the phone that you ask who else can provide support. Are there friends, are there family who provide support? And how they will communicate with these people?

Finally I think it's important to conclude on a factual note, to conclude on a plan, this is where we are, this is what we are going to do next. It can go this way, it can go that way, but this is what we are going to do next. And then also to promise an approximate time for the next contact. So that people have a reassurance of when you're next going to contact them and when to expect it.

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So for example you might say to them "He was more drowsy today and a bit more confused at times"; you're starting with the facts but you're keeping it simple. And then you empathise – "It must be so hard not to be with him at this time". I think one good question to ask people is "What would you do if..?" You know, and if they have got fears that they're voicing, it might be good to get them to think about how they would actually tackle certain situations.

And then finally as we've said, give them a clear steer about when you're going to call again, so they don't fret anxiously waiting wondering whether you're going to call them or not. So say "I will call you again tomorrow around 6pm but if there is a big change before then we will call you sooner." And that way, they feel safe.

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Finally what do you do if a patient suddenly becomes distressed? Lets say they get very breathless or they get a lot of pain suddenly. I think it's really important for someone to stay with the patient who's really experience if possible, while someone else prepares medication. It's very easy to be running around all over the place and to give someone a sense of anxiety. On the other hand, someone stays with them, especially if it's someone with a bit of experience, can project a certain calm.

Calm is contagious, and that calms patients down. So if possible have someone stay with the patient with another person acting as a runner to prepare the medication.

If necessary, you can give the patient 5 or 10 mg of midazolam subcutaneously or, if they're in shock, because let's say for example they're having a big bleed you have to give it intra-muscularly because when they're in shock medication doesn't get absorbed.

And if the patient is still distressed 15 minutes later, you repeat the injection. So it's important to stay with the patient and to have a very clear plan and to have the medication prescribed beforehand.

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So I think I just want to say one last thing before we finish. Nothing that we do when we're caring for somebody who's dying will take away the pain of death for that person or for their loved ones. It is a time which those people will remember all their lives. But the things which we can do at this time can give the patient a dignified and comfortable end and it can really be transformative for them. A situation that is usually scary and frightening can become one where they feel comfortable and at ease and that is a very rewarding thing to do.

Remember that the memories will stay with the family forever and therefore getting end of life care right really matters.

Finally, I just want to point you to a number of resources which will help you to read further about the things we've been talking about today. A number of guidelines and for example, about things like how to do difficult conversations. These things you have to do again and again and you have to witness other people doing them so that you get your own style. But it's really useful to read around them as well. Thank you very much.